

## **White Paper**

### **Implementing the People Living with HIV Stigma Index in New Jersey**

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#### **Acknowledgements**

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## Background

### The People Living with HIV Stigma Index

**About the Stigma Index.** The People Living with HIV (PLHIV) Stigma Index (hereafter “the Stigma Index” or, simply, “the Index”) was developed by a consortium of international organizations following the Greater Involvement of People Living with HIV (GIPA) principle, which supports the active participation of PLHIV in research and other activities that influence their health and well-being (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2007; UNAIDS, International Community of Women Living with HIV - Global [ICW], & Global Network of People Living with HIV [GNP+], 2017). The Stigma Index serves two primary goals. First, it is a comprehensive data collection tool, designed to elicit information on participants’ experiences with HIV-related stigma across a range of life experiences and domains. Second, it is an intervention which provides empathetic support to PLHIV and encourages advocacy on their own behalf (UNAIDS et al., 2017). The Index achieves this latter goal by training PLHIV as interviewers to administer the tool and by including survey questions and providing resources on HIV-related resources and advocacy in the data collection process. Since the project’s launch in 2008, the Stigma Index has been administered in more than 90 countries around the world and has been translated into 54 languages (UNAIDS et al., 2017). According to official estimates, as of 2013, more than 1,300 PLHIV had been trained as interviewers and the Index had been administered to more than 45,000 PLHIV worldwide (UNAIDS et al., 2017).

**Becoming a Data Collection Partner.** Implementing data collection using the Stigma Index requires a partnership between the PLHIV Stigma Index International Partnership (i.e., GNP+, UNAIDS, and ICW) and a research team subject to oversight on the ethical conduct of research, informed consent, and confidentiality. Employing the GIPA principle, conducting face-to-face interviews, providing referrals, and sharing results with the international community help to ensure that the data collection process is more than just an “academic enterprise” and that the findings will be used to improve the lives of PLHIV (UNAIDS et al., 2017).

### New Jersey Study Partners

The success of the implementation of the Stigma Index in New Jersey resulted from the close collaboration and partnership of a wide range of stakeholders. Figure 1 provides a schematic of the project’s organization and reporting lines. The roles of key participants are described in the sections that follow.

**The New Jersey HIV/AIDS Planning Group (NJHPG).** NJHPG is a collaborative comprised of representatives of governmental and non-governmental service providers, affected communities, and consumers that was formed by the New Jersey Department of Health (NJDOH), Division of HIV, STD, and TB Services (DHSTS) to improve the efficiency of HIV preventive and care service delivery throughout the state (DHSTS, n.d.). Members of the NJHPG are required to participate in at least one of the group’s four standing committees, which include the HIV/AIDS Issues, HIV/AIDS Prevention and Care, Governance, and Gay Men’s Committees. In 2012, recognizing the profoundly negative role that stigma continues to play in the HIV epidemic, members of the Issues Committee recommended establishment of the Stigma

Workgroup as a means of studying HIV-related stigma in New Jersey and offering recommendations and interventions as a way of lessening stigma's impact on the health and well-being of PLHIV throughout the state (NJHPG, 2012). Under the leadership of the then-chair, Ms. Deloris Dockery (who, as a member of GNP+, was directly involved in the development of the Stigma Index), the Stigma Workgroup began the process that would lead to implementation of the Stigma Index in New Jersey.

**Rutgers University's School of Nursing.** Rutgers' School of Nursing (SON) became involved with implementation of the Stigma Index when Dr. Ann Bagchi took over as chair of the Stigma Workgroup and was selected as project director for the NJDOH-funded study, *Implementing the PLHIV Stigma Index in New Jersey*. SON drafted the study protocol, which was approved and overseen by the Rutgers' Institutional Review Board (IRB). Dr. Bagchi served as the study director, with Dr. William Holzemer (Dean of SON) serving in an advisory capacity and as a member of the Steering Committee (described below).

Other staff members hired as temporary Rutgers employees for purposes of the project included a project coordinator (Mr. Dwight Peavy), a project manager (Mr. Kasny Damas), and two students to perform data entry. Mr. Peavy's responsibilities included conducting a focus group in the Northern region of the state, overseeing recruitment of interviewers, monitoring demographics of interviewees, tracking survey completion, and overseeing the work of the project manager and interviewers. Mr. Damas's responsibilities were primarily to assist Mr. Peavy with survey and payment tracking; however, Mr. Damas also assisted with data entry once targeted recruitment estimates were met. Given the volume of surveys and the time necessary to perform data entry (estimated at 30 to 45 minutes per questionnaire), it was necessary to hire two Rutgers students to assist with this task.

**The Steering Committee.** To assist in study design and implementation, the research team recruited a group of HIV service providers, advocates, and consumers active throughout the state, and with significant ties to key constituents and communities of PLHIV, to serve on a project Steering Committee. The goal was to recruit participants with extensive experience and understanding of the needs of consumers. Because committee members would not personally be involved in the day-to-day administration of the project, they would be able to provide a more objective view of the study process and findings. Although having HIV-positive serostatus was not a requirement for Steering Committee membership, participants included several HIV-positive service providers and consumers. A list of the organizations and areas represented by members of the Steering Committee appears in Table 1. Key tasks for the Steering Committee included (1) providing recommendations on study design, (2) assisting with recruitment efforts, (3) reviewing preliminary results, and (4) making recommendations on interventions to address HIV-related stigma based on study findings.

**Interviewers.** Members of the NJHPG Issues Committee and Stigma Workgroup provided assistance in recruiting interviewers. Following the original design of the Stigma Index, all interviewers were required to be PLHIV. Additional requirements included having a working telephone number; a high school degree, its equivalent, and/or demonstrated ability to read and write; and the ability to work legally in the United States. Potential interviewers submitted a completed job application and resume and were interviewed by Mr. Peavy to assess interpersonal communication skills. Twenty-nine interviewers were selected and completed a required two-day

training session led by consultants from GNP+. The training provided background on the Stigma Index project and included role playing and sessions on human rights and HIV-related stigma, the informed consent process, and practice conducting interviews with the New Jersey version of the questionnaire. Interviewers received \$100 gift cards upon completion of each day of training and \$40 gift cards for each completed interview upon submission of all paperwork (i.e., completed questionnaire and documentation of incentive payments). Originally, the goal was to recruit up to 54 interviewers with the expectation that each would complete up to seven interviews; however, most interviewers were willing and able to complete more interviews.

**Interviewees.** Interviewees were recruited through the personal and professional networks of NJHPG Issues committee members (many of whom are HIV service providers who were able to inform consumers of the study through flyers posted in their workplaces and during client visits to the agency), Steering Committee members, and interviewers, and by word of mouth. Interviewees could either complete the survey questionnaire on their own or the interviewer could read the questions and complete the survey on the individual's behalf. Interviewees received a \$30 gift card upon survey completion.

## Methods

### Survey Development

The Stigma Index questionnaire includes three primary sections: (1) demographics; (2) experiences with stigma, discrimination, and advocacy; and (3) experiences with testing, disclosure, and access to services. Sections 2 and 3 include specific modules that address sub-topics within these broader themes. For example, Section 2 includes the following modules: (2A) experiences with stigma/discrimination from other people; (2B) access to work, health, and education services; (2C) internal stigma; (2D) rights, laws, and policies; and (2E) effecting change. Although the majority of the questionnaire is limited to multiple choice questions, Section 3 includes two modules in which to record open-ended responses to questions regarding the problems and challenges that PLHIV face, the strengths and opportunities participants feel they have as a result of the HIV epidemic, and any other points the participant would like to mention.

The questionnaire was designed as a standardized data collection tool to allow comparison of findings across study sites and within an international context, while at the same time allowing for adaptation to the needs of the local context. As such, while the core questions and content must be retained, researchers can change the wording in Section 2D to address the laws and policies relevant to the geographic area of the study and can add content, as needed, to address local concerns. For example, in the first North American roll out of the Stigma Index (in Detroit), researchers included a module and additional questions addressing the experiences with HIV-related stigma among participants who had been previously incarcerated. SON researchers developed a draft of the New Jersey version of the Stigma Index questionnaire, which was then examined by consumers living with HIV through two focus group interviews (one held with consumers from the Central/Southern regions of the state and the other with consumers from the Northern region). Researchers made minor adjustments to the questionnaire based on this feedback prior to submitting the questionnaire to the IRB for approval. The final version of the New Jersey Stigma Index questionnaire is included as Appendix A of this report.

## **Sampling**

A unique feature of New Jersey's implementation of the Stigma Index was its statewide approach to data collection. One of the primary goals for implementing the Stigma Index in New Jersey was to recruit a sample of interviewees that would be as representative as possible of the population of PLHIV throughout the state. As such, the sample size and recruitment approach relied on data published by DHSTS regarding the geographic and demographic distribution of PLHIV in New Jersey as of December 31, 2013 (the most recent data available at that time). To ensure adequate sampling of consumers throughout the state, SON derived a sample size that would capture 1% of the number of cases of PLHIV per county, for a total targeted sample of approximately 375 (Table 2). In addition, recruitment took a targeted approach to capture roughly the distribution of PLHIV by known demographic characteristics (Table 3). Finally, in an effort to be inclusive of sub-groups who are frequently excluded from traditional research studies, recruitment efforts focused on key populations identified by members of the Steering Committee as important to target (Table 4). The study used quota sampling at the county level but a more informal targeting recruitment process to sample participants by demographic and sub-group characteristics.

The final sample included 326 cases, with survey completion targets met in all of the largest counties and only 2 of New Jersey's 21 counties without any representation (Table 2). As shown in Table 3, the study sample included a larger percentage of women and people of transgender experience than estimated in the state as a whole (39.0% and 5.0% versus 33% and 0%, respectively), as well as more African American respondents (68.4% versus 51%, with subsequently smaller percentages of Latinos and Whites). The sample also included a significantly larger percentage of long-term HIV survivors (i.e., people living with HIV for more than 20 years - 45.1% versus 22%). However, the sample matched closely the percentage of PLHIV in New Jersey by age categories. Given the close approximation of age groups between the two data sources, the discrepancy in percentage of long-term survivors between the two sources is somewhat puzzling.

## **Data Collection**

Interviews took place between January and May of 2017. PLHIV who were interested in participating in the study as interviewees were first instructed to contact the study coordinator. Although there were few limitations on study participation (e.g., participants had to be 18 or older and able to provide verbal consent to be interviewed), screening was necessary to ensure that interviews were conducted within the limits set by county quotas and to ensure a diversity of respondents. Mr. Peavy then identified an interviewer available to conduct the interview and arranged a meeting place convenient to both. To this end, Mr. Peavy maintained contact information for interviewees (i.e., first name and phone number) only for as long as was necessary to arrange the interview, after which the information was destroyed. To protect participant confidentiality in line with the requirements of the IRB protocol, Dr. Bagchi did not receive any personally identifiable information on interviewees and each survey was matched to a receipt of gift card payment via a survey code pre-recorded on both the questionnaire and gift card receipt (e.g., Essex001 for the first survey completed in Essex County up to Essex100 for the last survey).

The bulk of the questionnaire consists of closed-ended, multiple choice questions; however, there were three sources of qualitative data used in the study. First, the Stigma Index survey instrument includes several open-ended questions for participants either to elaborate on answers they have provided or to collect information on specific topics (e.g., “What do you see at the main problems and challenges for PLHIV in relation to HIV testing and diagnosis?”). Second, one of the organizations assisting with recruitment efforts independently conducted a focus group among study participants regarding their perceptions of the study and shared the findings from that discussion with the research team. Thirteen people who completed the survey participated in the focus group, which was held shortly after all data collection had been completed. Finally, some of the interviewers took notes on the interview process and on additional information that study participants provided (i.e., in response to the final survey question, “Is there anything else you would like to discuss or share?”) and provided that information to the study team as well. Hence, the findings below include results from both quantitative and qualitative data sources.

The research team partnered with HIV service organizations throughout the state to complete the data collection process. A contact person from each agency was responsible for storing interview packets under lock and key. Packets consisted of (1) a hard copy of the questionnaire; (2) \$30 and \$40 gift cards for payment to interviewees and interviewers, respectively; (4) gift card tracking forms; and (5) a consent form, which the interviewee had the option of keeping (formal consent was obtained verbally under IRB approval). Interviewers picked up an interview packet from the contact at the partner agency and completed the survey with the interviewee at the pre-arranged meeting place, which was often in a private location on the premises of the partner organization, at the interviewee’s request. Interviewers were responsible for providing interviewees with their payments upon completion of the survey and returned the gift card receipt and the completed questionnaire to the partner agency, at which time they received their \$40 payment. Study partners then submitted the completed questionnaires and receipts either to Mr. Peavy or directly to Dr. Bagchi. Dr. Bagchi maintained all gift card receipts and assigned the completed surveys to data entry staff. (A list of partnering agencies and individual contact persons, by county, is included in Appendix B. The tracking and consent forms appear in Appendix C.)

## **Data Entry**

Because the completed survey contained no personally identifiable information and due to the fact that four staff members (i.e., the two Rutgers students, Mr. Damas, and Dr. Bagchi) were performing data entry tasks simultaneously, data were originally recorded in an Excel file using Google Sheets. Dr. Bagchi then converted that file into an SPSS<sup>®</sup> data file for data cleaning and analysis. All statistical analyses were performed using SPSS<sup>®</sup> Statistics Version 24.0.0.0 (IBM<sup>®</sup> Corporation, 2016).

## **Findings**

The following sections present the major findings based on the 326 surveys completed. Most of the quantitative findings are presented in tabular format, as referenced in the narrative. However, those findings based on individual questions in the survey or those based on a small number of respondents are presented only in the text and do not appear in separate tables.

## Results from Quantitative Data Collection

**Demographics and background characteristics.** In addition to the basic demographic data presented previously, the first section of the questionnaire asked about relationships, availability of support, and perspectives on the future.

**Relationship status and support.** With respect to interpersonal relationships, although 23.3% of respondents reported that they were married and another 15.3% were in a relationship, the majority (52.1%) were single at the time of the survey and another 7.1% were either divorced/separated or widowed (4.3% and 2.8%, respectively) (Table 5). Subsequently, only 48.8% of interviewees said that they were currently sexually active.

Participants were asked to report how often over the prior 12 months they had support from others regarding a number of needs (Table 6). Regarding the availability of support if the individual were confined to bed, only 48.2% of participants said they had someone to provide this type of assistance “all” or “most” of the time. For all other measures, the majority said they had support at least most of the time, with a low of 53.6% for availability of someone to take them to the doctor to a high of 72.4% for someone to show them love and affection.

Finally, participants were asked about their optimism for the future. One hundred and ninety-six (60.1%) said they thought they would be better off three years from now and 33.4% said things would be about the same. Only 4.6% said they thought they would be worse off in 2020.

**Education, economic status, and insurance.** Compared with the overall population of New Jersey residents, those included in the study sample were generally of lower socioeconomic status, as reflected in levels of education and income. The majority of study participants (54.9%) had completed secondary school; however, the wording of the Stigma Index survey does not allow for determination of how many of these individuals actually graduated with a high school degree (Table 7). Another 30.4% had completed at least some college coursework and an additional 5.8% had graduated from college. Similar numbers of individuals completed school in the primary grades (3.7%) and after a post-graduate program (3.4%).

Half of study participants (50.6%) were unemployed and not looking for work at the time of the interview and another 14.4% were unemployed but looking for work (Table 8). Among those working, 13.2% were working full-time and 11.3% part-time as employees, while the remaining were self-employed in either formal, casual (e.g., day labor), or informal (i.e., “under the table”) work (1.8%, 3.4%, and 5.8%, respectively). Average monthly income was \$1,345.69 (std. deviation = \$1,790.72 and median of \$900) reflecting an annual income of around \$16,148.28, just below the 2017 federal poverty level of \$16,240 for two people (Office of the Assistant Secretary for Planning and Evaluation, 2017). A further indicator of economic well-being included in the Stigma Index is a question on food insecurity, with respondents reporting, on average, 1.6 days per month in which any household member had not enough food to eat.

Finally, the majority of respondents stated that they were covered by Medicaid (60.1%) and/or Medicare (33.1%) at the time of the interview (Table 9). Only 4.6% were uninsured and 9.2% said they received all of their care and services under the Ryan White HIV/AIDS Program.

The remainder had either public insurance (e.g., a county-based plan) (1.8%), a plan purchased through the Affordable Care Act (ACA) Marketplace (4.9%), coverage through an employer (7.7%), other private insurance (3.4%), or some other coverage (9.2%). Among the 30 respondents who reported some “other” insurance coverage, the majority of them mentioned some type of private insurance coverage (e.g., Aetna or Horizon), but three said they received Charity Care and one mentioned military insurance. Overall, 80.1% said that they had dental insurance, but 4.6% were unsure of their dental health coverage.

**Group identification.** The Stigma Index asks about a number of identities which may or may not be a source of stigma other than one’s HIV status (Table 10). It is important to assess group membership to be able to design interventions that can address sources of intersecting stigma (defined as “overlapping, multilevel forms of stigma and discrimination” that result from membership in multiple marginalized groups) to which PLHIV may be subjected (Logie, James, Tharao, & Loutfy, 2011). Respondents were asked to indicate to which of these groups they have ever belonged. Among these groups, respondents in New Jersey were mostly likely to identify as heterosexual (48.8%), followed by mentally ill (34.0%), homeless (33.4%), formerly incarcerated (31.3%), and as a man who has sex with men (31.3%). Of note, while 102 respondents stated that they had ever been incarcerated, only 49 reported that they had spent time in custody in the past 12 months. Other common categories were living in poverty (28.8%), gay/lesbian (26.7%), injection drug users (23.6%), sex worker (15.6%) and bisexual (14.9%).

**Disability status.** Participants were asked about physical, mental, and learning disabilities they may have. One hundred forty-two (43.6%) reported any type of physical disability aside from general ill health associated with their HIV status. The most commonly cited problems included arthritis/back or knee pain, high blood pressure, neuropathy, asthma or chronic obstructive pulmonary disease (COPD), and sequela from stroke. Respondents were also specifically asked about co-infection with Hepatitis C; 7.7% said they were currently co-infected, 16.0% said they were previously infected but successfully treated, 71.2% said they were not infected, and 2.1% did not know. Mental disabilities were frequently reported, with 141 individuals (43.3%) citing some type of mental disability. Depression was the most commonly cited disorder, with bipolar disorder, anxiety (including post-traumatic stress disorder), and attention deficit disorders also frequently mentioned. Only 52 (16.0%) of participants reported any type of learning disability, most commonly attention deficit, difficulty concentrating, and problems with reading and writing. Assessment of health literacy using the Single Item Literacy Screener (Morris, MacLean, Chew, & Littenberg, 2006) found that 107 individuals (32.8%) demonstrated low health literacy (i.e., needed assistance reading health-related materials from their doctor or pharmacy at least “some of the time”).

**PROMIS-29.** The New Jersey version of the Stigma Index survey included the 29-item Patient-Reported Outcomes Measurement Information System (PROMIS-29) questionnaire. The PROMIS-29 collects information on seven domains of well-being (i.e., physical function, anxiety, depression, fatigue, sleep disturbance, ability to participate in social roles/responsibilities, and pain interference) and is a well-validated instrument for assessing health status (Health Measures, 2017). Each domain includes four items which are scored from 1 (least disabling) to 5 (most disabling), along with an overall pain scale (i.e., “On a 10-point scale, where 0 is no pain and 10 is the worst pain imaginable, how would you rate your pain on average?”). For each respondent, the items for every domain were added together to create a

summary score (ranging from 4 to 20) and then the domains were added to create an overall score (ranging from 28 to 140); the pain scale is scored separately.

Among study participants, the domain with the highest level of disability was sleep disturbance, with a mean of 12.1 (Table 11). Among those items, 18.7% of respondents said that their sleep was “not at all” refreshing and 12.6% rated their sleep quality as “poor.” Similarly, when asked whether sleep was a problem and whether they had any problem falling asleep, 14.6% and 15.3% respectively responded “very much” on each question. Fewer than 10% of respondents endorsed the most extreme category on any of the other individual items in the PROMIS-29 questionnaire; participants had least difficulty with physical function (mean of 6.9). On a daily basis, participants live with an average pain of 4.6 on the 10-point scale, but 71 participants (21.8%) reported their average pain as an 8 or higher.

**Experiences with stigma and discrimination.** The Stigma Index was designed to collect information on the sources and consequences of both external and internal stigma. The questions on external stigma addressed attitudes and behaviors directed toward the individual and their effects. Questions related to internal stigma examine participants’ self-perceptions and fears related to their HIV-positive status.

**External stigma.** Participants were asked how frequently over the last 12 months they were subjected to a number of stigmatizing and/or discriminating behaviors (Table 12). By far the most common, 51% said that they had been gossiped about at least a few times, with 16.3% stating that this had happened “often.” Other common experiences that happened at least a few times to at least 10% of participants were being verbally insulted, harassed or threatened (26.4%); being excluded from social gatherings (21.8%); being discriminated against by other PLHIV (17.2%); being excluded from family gatherings (15.2%); experiencing sexual rejection (14.5%); and being physically harassed or threatened (11.0%).

Few participants said that they had been stigmatized or discriminated against in health care settings. The largest percentages were for physicians (6.1%), receptionists (5.5%), and emergency department staff (5.2%) (Table 13). Fewer than 10 study participants said that they had been denied family planning services (2.8%) or sexual and reproductive health services (2.5%) in the past 12 months.

Among those who had experienced any of the types of stigma or discrimination asked about, participants were asked why they thought this occurred (Table 14). The most commonly cited reasons were fear of transmission through casual contact (39.0%), general fear of infection (31.0%), perception of HIV as shameful and belief that one should not associate with a person living with HIV (30.7%), and disapproval of one’s lifestyle or behaviors (22.1%). Another 12.0% cited religious beliefs or “moral” judgments as the cause of stigmatization and 4.6% said it was because they looked sick with symptoms commonly associated with HIV. However, 18.1% of participants said they did not know why they had been subjected to any of the stigmatizing experiences asked about in Table 12.

Participants were asked if they thought they had been subjected to stigma or discrimination on the basis of any other groups to which they belong; respondents could cite more than one reason (Table 15). The most commonly cited reason was for their status as a gay

man, man who has sex with men, or lesbian (26.1%). Other common categories were as a formerly incarcerated person, being unemployed, and being homeless (all at 18.7%), being diagnosed with a mental illness (17.5%), living in poverty (16.3%), being a member of an ethnic minority group (16.05%), and using injection drugs (14.4%). Although respondents were asked to identify the *main* reason (other than their HIV status) for experiencing stigma, the vast majority of respondents said they thought that all of the reasons they cited were equally relevant.

Finally, participants were asked about the sequelae of stigma and discrimination (Table 16). Of those who had experienced stigmatizing behaviors, mental health effects were the most commonly cited, with 52.5% of respondents saying they had experienced depression due to stigma, 45.4% saying they had anxiety, and 39.9% stating that they had withdrawn from friends and family. Ninety-three participants (28.5%) noted that stigma led to reductions in exercise, physical activity and sleep as well. In considering the current goal of 90% of PLHIV achieving an undetectable viral load (UNAIDS, 2017), it is important to note that 76 respondents (23.3%) said that stigma and discrimination had led them to skip doses of their medications and 48 (14.7%) said they had avoided health care.

**Internal stigma.** The Stigma Index also examines internal stigma and how HIV infection affects a person's feelings about themselves and their behaviors. With respect to feelings, participants reported that in the past 12 months they have most commonly blamed themselves (53.7%), felt angry (47.2%), had low self-esteem (39.0%), felt ashamed (36.5%), felt guilty (26.7%) and blamed others (24.5%) (Table 17). Behaviorally, more than one-quarter of respondents stated that, in the past 12 months, they have isolated themselves (32.2%), decided not to share their status with someone who might have provided support (30.4%), decided not to have sex (23.0%), and decided not to have any (more) children (25.8%) (Table 18). Another 23.0% said they had avoided social gatherings as a result of their HIV status.

Fears of stigmatizing behavior were common among study participants (Table 19). Half of respondents (50.3%) said that in the past 12 months they feared being gossiped about at some point. One hundred forty-seven participants (45.1%) feared that someone would not want to be sexually intimate with them due to their status and 41.1% feared their status might be shared online or via social media without their consent. Fears of being threatened and assaulted were also common, while fewer respondents feared being denied health care (19.0%). These results were consistent with the findings noted earlier regarding actual experiences of stigmatizing behavior (i.e., gossip being the most common type of external stigma and health care provider stigma relatively uncommon).

The majority of study participants (77.6%) had seen an HIV prevention campaign in the previous 12 months, but reactions varied (Table 20). For the most part, participants found the campaigns encouraging (50.3%) and empowering (45.1%). However, some found them to be stigmatizing (8.9%), frightening (5.2%), or shaming (6.4%). There were no data collected regarding the specific campaigns that elicited these negative reactions.

**Policy and effecting change.** The section of the survey addressing policies and activism assessed awareness of one's rights as a person living with HIV as well as personal involvement in activities to promote the health and well-being of PLHIV.

***HIV-related policy.*** Patients were asked about laws and policies related to their HIV status. A minority (40.2%) had ever heard of the *2011 Declaration of Commitment on HIV/AIDS* (UNAIDS, 2011) and fewer than half (48.9%) of those who had heard of it had ever read it. However, the majority (58.0%) of study participants had heard of the Americans with Disabilities Act and 50.8% of those individuals had ever read it. Awareness of the ACA was much higher, at 92.0%, but only 21.5% of respondents said that the ACA had affected their insurance coverage via either a change in prescription coverage, cost, or provider service. However, 33.7% of respondents said that they thought the ACA would lead to better care for them in the future; 6.2% said they thought their care would be worse, 16.9% thought it would be about the same, and 29.8% were not sure about the law's likely effects. Note that the surveys were all completed prior to widespread news coverage regarding efforts to "repeal and replace Obamacare."

Participants reported few violations of their rights in health care settings related to their HIV status. Thirty-three individuals (10.1%) said they had been denied health insurance due to their HIV status and 24 (7.4%) said they had been forced to submit to a medical procedure (including HIV testing). Overall, 73.9% of respondents said that they had not experienced any of the health-related rights violations assessed in the survey. Similarly, 81.9% said that they had not had their rights abused in other contexts in the prior 12 months, although 30.6% said they had at least once been falsely accused of not disclosing their HIV status to a sexual partner. Among those who reported an abuse of their rights within the past year, only 7 (28.0% of those reporting some type of abuse and 2.1% of the sample overall) stated that they had sought any legal remedy, six of whom had sought assistance from a governmental employee and five of whom contacted a politician.

***Effecting change.*** Study participants have actively addressed stigmatizing behavior within their own lives. When asked if they had personally ever confronted someone in the past 12 months who had been stigmatizing and/or discriminating against them or against another person with HIV, around 40% responded that they had. Only 14.7% were unaware of any organization they could turn to if faced with stigma or discrimination. The most common sources of support of which participants were aware included support groups (72.7%), local AIDS service organizations (68.7%) and networks of PLHIV (51.5%) (Table 21). However, only 97 respondents (32.2%) said they had ever requested help from any of the organizations mentioned in the survey.

The majority of participants (80.1%) said that they had provided support to other PLHIV within the prior 12 months. In most cases, that support was emotional (73.9%), but practical support and referrals were also common (44.4% and 40.5%, respectively). Although most participants said they had not sought help from HIV-related service organizations and groups, the majority (61.3%) said that they were members of such groups and 39.3% said that they had volunteered in programs or projects to provide assistance to other PLHIV. Furthermore, 19.9% said they had been actively involved in efforts to develop legislation, guidelines, or policies related to HIV. These findings suggest that, overall, participants have been more commonly in the position to offer assistance than to need it personally.

When asked whether participants felt that they had the power to influence decision-making related to laws and policies affecting PLHIV, the sense of empowerment was strongest at

the local level (Table 22). One hundred fifty respondents (46.0%) said they felt empowered to affect local projects, with smaller numbers feeling empowered to affect other aspects of law and policies. However, 36.8% felt they did not have the power to influence any of the other types of decisions assessed in the survey. Although there was no direct assessment of political activity (e.g., involvement in political campaigns), the majority (79.8%) stated that they were registered to vote.

A final question related to activities supporting the rights of PLHIV asked participants to rank eight items on their importance in addressing stigma and discrimination. However, most participants either did not understand the instructions or believed that all items were equally important because they provided the same score for each item mentioned (e.g., all “1s” or all “8s”) (Table 23). The wording of the question may have been confusing as well. The instructions stated, “Rank the following in importance from 1 to 8,” so it may have been unclear whether “1” or “8” indicated the most important item. Regardless, several participants wrote on the hard copy of the questionnaire, “They are all important.” Other issues specifically mentioned in open-ended responses included providing services (e.g., for mental health, poverty, homelessness, trauma, and food) and decriminalizing HIV. Several individuals stressed the importance of educating the wider community through public service announcements.

**Testing and access to services.** The next section of the Stigma Index survey asked about experiences related to HIV testing and diagnosis. This section also addressed issues of health status and experiences with disclosure. Special topics in this section included experiences with family planning/women’s experiences with pregnancy while living with HIV and stigma experiences while incarcerated.

***HIV testing and treatment.*** The first question in this section asked respondents to think back to the time they were diagnosed with HIV and their reason for HIV testing at that time. While respondents could select more than one reason for testing, the most common was “just wanting to know” their status (34.4%) (Table 24). Other common reasons were referrals due to suspected HIV-related symptoms or from clinics for sexually transmitted infections (16.0% and 11.7%, respectively) and family-related motivations (a family member has tested positive for 11.3% of participants and in 14.1% of cases a partner or family member encouraged the individual to test). Other reasons cited in open-ended responses were having been tested during a blood drive and wanting to receive an incentive payment (e.g., gift card for testing). One person said they were inspired to get tested after watching a movie about HIV testing.

For the majority of study participants (54.0%), the HIV test they received at the time of diagnosis was the first time they had ever been tested; 37.7% had at least one prior test that was negative and 4.0% had tested but did not receive their results (Table 25). In most cases (70.2%), the respondent made an independent decision to take an HIV test, but in some cases the test was taken under pressure (8.0%), through coercion (6.6%), or without the individual’s knowledge (6.6%) (Table 26). Although around one-third of individuals (35.0%) reported receiving both pre- and post-test counseling, nearly an equal number (30.1%) did not receive any counseling at the time of diagnosis; the remainder received only pre- or only post-test counseling (3.7% and 18.1%, respectively) (Table 27). For the majority of respondents (62.0%), there was little delay (zero to three months) between the time they thought they should take an HIV test and the time

they actually took one (Table 28); however, 13.8% of study participants said they waited at least one year to test.

Most participants said that fears about how people might react led to hesitation to get tested. Of these fears, the most common were the fear of being shunned by family or friends (58.6%), fear that others might think of them as someone who engages in risk taking behavior (34.4%), fear that others would find out that they had engaged in such behaviors (25.5%), fear that their partner would leave (23.6%), and fear that they would not be able to get married (22.4%) (Table 29). Fears of violence and community rejection were also common. The majority of respondents (66.3%) said they entered care within three months of their diagnosis, but 14.1% said that they had waited at least one year before seeing a health care provider (Table 30). Of those who delayed care, the most common reasons cited were that they were not ready to deal with their diagnosis and the fear that someone they knew might see them at the health care provider's office. These were also the most common reasons cited for any gaps of 12 months or longer that participants had experienced in their care; however, such gaps were relatively uncommon in the study sample, with 65 people (19.9% of the sample) saying they had not seen a health care provider in the prior six months or longer. In general, common open-ended response explaining gaps in care related to fear, a high CD4 count, denial, drug abuse/addiction, lack of trust in the healthcare system, and insurance issues. One participant stated that she delayed entry into care because she thought she could just pray and would be fine.

The final question in this section of the survey asked about fears related to possible legal actions that might be taken against an individual who tests positive for HIV. Respondents were asked to state whether such fears were "very," "somewhat," or "not" reasonable based on three scenarios (Table 31). Fifty-three percent of respondents said it was at least somewhat reasonable for a person who feels otherwise healthy to avoid getting an HIV test for fear of being prosecuted if the test came back positive (with 19.9% stating this is a "very reasonable" response). Similarly, 55.2% said it was at least somewhat reasonable to avoid disclosing one's HIV status to a current sexual partner for fear of prosecution; 51.9% also said it was reasonable to avoid receiving treatment.

***Experiences with disclosure.*** In cases where their HIV status had been disclosed, the majority of survey respondents said they had either disclosed to others themselves or had consented to have their HIV status shared by someone else (Table 32). Except among family members and friends, fewer than 5% of respondents said that someone else had disclosed their status without their consent. Unconsented disclosure occurred with adult family members, children, and friends or neighbors among 12.6%, 6.1%, and 10.1% of respondents, respectively. The majority of respondents said they had never felt pressured either by other PLHIV (71.2%) or people not living with HIV (69.6%) to share their HIV status; however, the remainder reported that they had experienced this type of pressure at least once. Among those who had disclosed their status, respondents reported that in most cases the individual had either behaved no differently toward them or had been at least somewhat supportive (Table 33). The most discriminatory reactions were from family members and friends. Most respondents (59.2%) said they found disclosure to be an empowering experience, although 22.1% found this not to be the case and another 16.3% said the question was not applicable, suggesting that they had not disclosed to anyone.

Within the HIV service arena, although only 8.6% of respondents said that a health care professional had shared their status without their consent, 30.7% were unsure if this had ever occurred. Similarly, only 7.7% said that a staff member of an ASO had shared their status but 27.3% were unsure. Finally, while 58.9% stated that they felt confident that their medical records were kept completely confidential, 7.1% said they clearly were not and another 28.5% were unsure about the confidentiality of their records.

***Health status and treatment.*** Overall, participants reported good health, with 73.9% reporting their current health status as at least “good”; only 72 individuals (22.1%) rated their health as “fair” and 12 (3.7%) said it was “poor” (Table 34). The majority had been to an office visit or had lab work or a blood test within the past six months (85.9% and 82.2%, respectively) (Table 35). Around three-quarters (75.5%) said their viral load was undetectable on their last test and 55.9% reported their CD4 count at 500 or higher (Tables 36 and 37). Likely reflecting these positive health indicators, although most participants (89.9%) said they were currently taking antiretroviral therapy only 30.1% were on treatment to prevent opportunistic infections.

Participants largely had positive views regarding their communication with health care providers and the efficacy of their care. Although only 81.3% said they had had a constructive conversation regarding treatment options in the past 12 months, more than 90% felt that their health care provider supported them in their decision making and helped them to understand their treatment regimen (Table 38). However, areas for improvement included discussions regarding adherence and sexual health, emotional well-being, and drug use; 77.9% said they had had a constructive conversation about the former in the prior 12 months and 69.0% said the same about the latter. Ratings of support from health care providers and case managers/social workers and the fit of their treatment regimen ranged from 79.8% to 86.2% (Table 39).

Only 50% of study participants stated that they have children, and the majority of these respondents (59.5%) said that they had not received counseling about reproductive choices since their diagnosis. A minority of participants said they had ever been advised not to have children (7.4%), had been coerced into being sterilized (3.1%), or had been told that their access to contraception was conditional upon the use of certain forms of contraception (4.3%). Among the 47 women who said they had been pregnant while HIV-positive, 48.9% said they had not been given antiretrovirals to prevent mother-to-child transmission, with three women stating they had been refused such treatment.

***Experiences while Incarcerated.*** Although 102 study participants identified as having been incarcerated at some point in their lives, there were some conflicting data regarding the number incarcerated in the past 12 months; 49 people responded as such to one survey question asking about recent incarceration, but 76 individuals completed the separate module for those with a recent incarceration (Table 40). Among the four women who said they had given birth while incarcerated; three reported having their sentencing enhanced due to their HIV status and two said they had been “strongly advised” to give their baby up for adoption. While the majority of those who had ever been incarcerated did not experience specific stigmatizing behaviors during their incarceration, more than one-third of these individuals said that they were denied access to HIV-related health care services, were subjected to experiences that exposed their status, or otherwise had their status disclosed by prison staff or other inmates (Table 40).

## Results from Qualitative Data

**Open-ended responses to survey questions.** One set of questions in the survey asked whether participants had ever tried to resolve an issue of stigma or discrimination, either by themselves or with the assistance of others. Respondents were asked to describe the situation, who was involved, and how the matter was resolved. In addition, the final sections of the Stigma Index survey were comprised of open-ended questions regarding problems and challenges that PLHIV face relating to HIV testing and diagnosis, disclosure and confidentiality, antiretroviral treatment, and having children while HIV-positive, as well as strengths and opportunities respondents perceive relating to the HIV epidemic. The following sections summarize those findings and include some illustrative quotations in the words of study participants (highlighted in italics).

***Resolving issues of stigma and discrimination.*** When asked about situations relating to stigma and discrimination in which participants tried to intervene, the most common responses were correcting false information/myths about HIV (e.g., *“A person was giving information about how HIV is transferred and it was wrong”* and *“I overheard someone say don’t hug, drink after, and sit next to them because they have HIV”*) and addressing gossip (e.g., *“Another person had HIV and a person said, ‘they have the package, don’t touch them’*). However, other situations were related to homophobia (e.g., *“anti-gay remarks being made at a Wellness group by the reverend running the group”*), racism, homelessness, and immigration status. In one case, a respondent said they had to intervene with their sister because she was *“jealous of the perks of being HIV-positive [although] she doesn’t want to get the virus.”* In many cases the respondent was able to deal with the situation themselves. The most common sources of outside assistance were staff from HIV/AIDS service organizations, case managers, health care providers, support groups, and family/friends. In almost all cases the situation was resolved by providing information/education and/or directly confronting the individual; however, in one case the situation was reported and the State conducted an investigation and in two other cases the perpetrator was fired.

A related set of questions asked participants why they felt they either could or could not influence decisions relating to the rights of PLHIV and policies affecting them. Among those who responded to the question saying they felt they could not make a difference, fear of taking a stand and the sense that they are powerless as an individual were the most common reasons. However, those who answered the question were far more likely to say that they felt they could make a difference. Reasons given were because they (1) were part of a larger organization/group, (2) were educated about HIV and living with the virus and could draw on that experience, (3) had access to resources (e.g., legal assistance), (4) could participate in the democratic process (e.g., voting, contacting Congress/the Governor, participating in marches, signing petitions, and presenting at meetings), and (5) could take part in studies.

***Problems and challenges relating to HIV testing and diagnosis.*** The most common challenge that participants cited relating to HIV testing was a sense of fear and denial that people may experience, which may result in their decision to avoid HIV testing; 90 participants mentioned these fears in this section of the questionnaire. As one participant put it, *“Some people choose not to know their status; they are afraid to face their fears.”* Other barriers relating to HIV testing included the fear of stigma and/or discrimination and the need for more

access to testing. With respect to the latter, suggestions that respondents made included providing more 24-hour testing sites, expanding mobile testing, improving access to home tests, and making HIV testing a more routine part of health care. Some participants noted that testing programs tend to focus only on those considered to be at highest risk and suggested that funding to expand testing was insufficient “...or limited to certain populations.” Several participants suggested focusing testing campaigns on the benefits of testing (e.g., helping people to be “...open enough to get tested without being given an incentive... [to] ... know their diagnosis for their health”) and providing more information on the locations of testing sites. Finally, participants suggested a need to provide more counseling support while clients are awaiting test results and in preparing those who test positive for initiation of antiretroviral therapy (e.g., offering psychological preparation for the reality of life-long treatment that requires frequent blood testing). In general, there is a feeling that health care providers need to be more cognizant of how they address the everyday care of PLHIV. Advice that one participant had for people testing positive was, “[Understand] that after being diagnosed, everything you complain to doctors about will be considered something to do with your status, which is not true.”

**Problems and challenges relating to disclosure and confidentiality.** The most common barrier to disclosure (mentioned by 87 participants) was fear associated with rejection and discrimination/stigma that one may face in sharing one’s status. A comment from one participant was illustrative of this sentiment: “I will not disclose my status because I fear my church and community will disown me. I hear the way they talk about others that are HIV-positive.” Related concerns included lack of assurance of confidentiality (e.g., “...sharing of information from one medical worker to another without my consent”) and knowing who you can trust/avoiding gossip (e.g., “...being able to tell family and friends without your diagnosis being repeated”). Many participants noted that it should be the individual’s decision regarding whether, and to whom, to disclose, but several suggested a need for support and education to assist with the disclosure process. Summarizing several of these points, one respondent stated, “There should be more support groups and counseling for disclosure alone – is anything ever really confidential?”

Health care providers were generally seen as good about protecting confidentiality but four people mentioned a lack of privacy in the emergency department as a disclosure risk (e.g., “... having small rooms with a door, rather than a curtain so no one can overhear your private conversation. You will be more honest with your answers”). Similarly, a couple of respondents noted that having to go to specific sites known for treating patients with HIV carries a disclosure risk, suggesting the need for expansion of HIV care to other types of treatment settings (e.g., primary care). Finally, a number of participants stated that educational campaigns are needed to address myths that create barriers to disclosure (e.g., educating on the means of transmission to combat what people may see on television or social media).

**Problems and challenges relating to antiretroviral treatment (ART).** The most common problem mentioned in relation to ART (n = 58 participants) was dealing with the side effects of medications. As mentioned previously, several respondents suggested a need for more psychological support to prepare people for the side effects they might experience, as well as a way to improve testing rates. As one person put it, “Side effects are a reason some people don’t want to get tested and take medication, not understanding that all medications have side effects.” Another participant cited the challenge of “...understanding the pros and cons to medications, mainly the side effects as they relate to other health issues.” Other common medication-related

challenges were adherence and having to take the medications at the same time each day (including the fact that treatment is a life-long commitment) and the issue of pill burden (with several suggesting the need for the development of an injectable medication that could be taken every six months). Several also mentioned the difficulty in finding an effective medication regimen and the risk of mutations/resistance and suggested the need for counseling support to assist with such issues as adherence, mental health disorders, and substance abuse, which interfere with treatment.

Only a few participants mentioned stigma associated with ART. These concerns included the fact that others will know a person is taking ART based on their medication bottles or when picking up medications from the pharmacy, the fact that daily medications serve as a reminder of one's HIV status, and the need to inform family and friends of your status and medications in case you get sick. One participant noted, *"Although I receive free medication, I feel the costs are too high. I feel shameful because so many taxes and/or contributions are being spent on me,"* suggesting that internal stigma remains a challenge with ART.

Several study participants specifically mentioned the current policy environment and their concerns about the costs of ART. At least 30 people mentioned that co-pays and problems with insurance coverage can make treatment unaffordable. There was concern about the sustainability of New Jersey's AIDS Drug Distribution Program in light of debates about the health care system and insurance coverage. One participant mentioned a concern about *"...not having access to treatment and/or medications – always wondering if Ryan White or AIDS funding will be cut completely"* and another specifically stated the biggest challenge they saw was *"...making sure ADDP and other support programs continue under the current administration."*

***Problems and challenges relating to having children when HIV-positive.*** The majority of participants stated that there was no problem having children when you are living with HIV, with 26 participants specifically noting that it is best done by taking good care of yourself and seeking the guidance of health care providers. The biggest concerns that participants cited were fears that the child would be born with HIV and would blame the parents (e.g., *"My mother had me and I was born HIV-positive. I wasn't given a choice. I didn't ask for this and I blame both of my parents."*) or would somehow contract HIV after birth. Although many of these participants noted that it is possible to have children without transmitting the virus, several stated words to the effect that *"there is always a risk, even if you are careful."*

Although a number of respondents indicated that having children is a right and decision to be made by the individual, several said they would not personally take a risk of having a child born with HIV (e.g., *"I wouldn't do it because of fear – I don't trust the medications"*) and at least 15 specifically said that PLHIV should not have children. Some common statements on this latter point included the following:

- *"I don't have children but people should avoid having children when they are HIV positive."*
- *"Definitely no"*
- *"I don't think you should have children if you're positive, but that's just me. Why take a chance?"*

- *“It’s a selfish idea.”*

Based on the statements above, an apparently well-founded fear cited by several study participants was that they might not choose to have children out of the fear of people judging them for their decision. Several respondents said that adoption might be a better choice, but at least one stated that *“...adoption agencies see PLHIV as irresponsible.”* In addition to these concerns, one person stated they would not have a child out of fear that the child might be taken away.

In addition to the concerns cited above, other issues related to childbearing were the fear of becoming too sick to care for children and the belief that children create an unnecessary stress that could undermine one’s health. Other worries were the belief that the child might be teased because of their parent’s HIV status or that the children would react negatively once they found out their parent’s status.

***Personal growth and living with HIV.*** When asked if they felt they had grown or developed as a person because of their HIV diagnosis, 28 participants said they had not and another 27 either did not respond to the question or said they were unsure; the remaining 271 said they had in some way. Among those who said they had not grown, typical responses were the following:

- *“No, I struggle daily of fear of people finding out.”*
- *“No, my addiction has me stagnated.”*
- *“No, I struggle and the struggle is real. I just buried my son two months ago. I’m committing suicide on the installment plan. My addiction has the best of me.”*
- *“Absolutely not. I’ve been picked on, talked about, rejected by my family members. I am one of five children and the only one born with HIV. I’m not even accepted by my siblings.”*
- *“No. I feel that many things in life have been denied to me. I have not developed or grown as a result of losing opportunities that non-HIV positive people take for granted.”*
- *“No. I am still ashamed.”*

By far the most common response among those who said they had grown, 103 people said they had become better educated about their health in general, and about HIV specifically, and had learned to take better care of themselves. Other common responses were feeling stronger, more confident, and empowered. As one participant put it, *“Through our struggles come our strengths.”* Another respondent stated, *“I am not afraid to share my HIV status with people I just met. I finally got the concept that I have HIV, HIV does not have me.”* In general, there was a sense of greater self-acceptance (e.g., *“Being a long-term survivor has helped me prioritize what is important in life and given me more confidence in facing challenges of everyday life.”*). Many participants also reported more empathy and tolerance toward others, as well as a willingness to help others. For example, one participant stated, *“Yes! I now know how minorities feel by being treated poorly. Racism and treating people different! My eyes are open now!”* Another stated, *“I have become a beacon of light to those less fortunate and unaware. I try to connect to those unaware to proper people who can help.”* A number of people said they

appreciate life more and live life more fully. Several stated that they are more careful with sexual encounters and dating. Finally, a number said that their diagnosis had made them more responsible and helped them to stop abusing drugs and/or alcohol.

***Opportunities available to PLHIV and the community.*** Only 249 participants responded to this question, with 48 saying that they did not see any opportunities. As one person put it, *“I do not see opportunities resulting from the epidemic. The wording of such a question strikes as so many platitudes which are offered to PLHIV. The only purpose of such a state is to make people feel good about a very difficult situation.”* Among those who responded affirmatively, 71 responded that educating people about HIV was the most important opportunity that they could identify. Another commonly cited opportunity was the development of programs and support groups. Specific programs that were seen as needed included those to increase understanding and awareness of HIV, expansion of needle exchange and drug treatment, housing, and jobs training. A number of respondents said the HIV epidemic has allowed people to develop more of a sense of community, encouraging volunteerism, supporting one another, fighting discrimination, and encouraging members of specific groups to come together (e.g., women of color, gay men, and people of transgender experience). One respondent noted, *“HIV in our community afforded the opportunity to join several planning counsels, have our voices heard, and participate in studies to help change policies and stop discrimination and stigma.”* Other opportunities cited include increased access to care and improvements in antiretroviral medications, as well as interventions to improve preventing and testing.

***Other things to share.*** A number of respondents expressed a strong desire to participate in the study as a means of helping to end HIV-related stigma. Participants cited specific instances of healthcare provider stigma in this section, all of which occurred in the early days of the epidemic. Examples include the following:

- *“I was once discriminated against by a psychiatrist who refused to treat me because of my HIV status.”*
- *“During a massage therapy (in the 90s) I was fully clothed, but the massage therapist wore plastic gloves, which I thought was excessive for her need of protection. Also, some dentists wouldn’t accept me due to my HIV status.”*
- *“Back in the 80s and 90s I experienced stigma and discrimination in the hospital by being isolated from other patients. Nurses didn’t want to come into my room to feed me or give me medications. Sometimes I was never fed.”*

As noted in the quantitative findings, few study participants reported any recent problems of stigma associated with health care providers, but several mentioned in this section of the study that they were motivated to participate in the study based on these past experiences.

As in prior sections, some of the points that participants deemed important were addressing the needs of specific communities (in this case, Latinos and heterosexuals who may underestimate their risk for contracting HIV) and policy concerns. Specific policy issues raised in this section included concerns about health care coverage and insurance issues under the current federal administration, the need for quality control procedures in HIV care, and the need for increased funding for transportation, housing, and education/job training. When asked about

the main issues facing PLHIV, several mentioned insurance and treatment affordability and opportunities for expanding awareness and use of PrEP.

Several participants commented on the survey itself. One stated that the survey missed several important aspects of living with HIV. A few people said the survey was too long. At least one person noted that some of the questions were not relevant (e.g., questions on incarceration), which suggests they did not understand the skip patterns in the document.

**Findings from the focus group.** All of the focus group participants were African American, nine of whom were male and four of whom had been HIV positive for fewer than five years. Three of the participants were less than 30 years of age, three were 31 to 45, and the remaining seven were 46 or older. The report of findings consisted of a list of questions covered and bullet points summarizing findings. Overall, participants' priorities were to maintain their health and stay adherent to treatment plans. The types of stigma they experienced included depression/"self-hate", stereotyping, rejection, and dealing with people's misconceptions about HIV (e.g., unreasonable fears and myths, such as beliefs that only gay men contract HIV).

The types of programs and issues cited as important to participants included transportation, emergency housing, mental health/substance abuse services, food assistance, and education on recent advances in HIV. There is also a need, from these individuals' perspectives, for improved nursing services, enhanced confidentiality, and programs regarding sexual health and educating community members on HIV. A specific recommendation was for programs on relationships and how to communicate better with one's partner.

With respect to the Stigma Index study, participants said it reminded them of things they had forgotten and helped them address some internal stigma they had been feeling. Some repeated the earlier criticisms of the survey being too long and focusing too much on experiences during incarceration; there was also the feeling that some of the questions were repetitive. However, participants had a good impression of the survey overall, with 10 of the 13 giving it an above average rating for satisfaction, stating that they would be willing to participate in a similar study, and recommending it to a family member or friend.

When asked what participants would like to see "more of" regarding stigma and general HIV information, suggestions included a stigma study among people who are not currently infected, more discussions between HIV-positive and HIV-negative people, more television and radio ads, and more focus on younger people and those who are newly diagnosed. There was also a desire for more support groups and community awareness (e.g., encouraging churches to more openly admit PLHIV and organizing marches like the AIDS Walk). One specific recommendation was for more African American leaders to discuss HIV more openly.

**Findings from interviewer notes.** A review of the interviewer notes brought up a number of ideas and themes. Participants commonly expressed a hope that their involvement in the study would help to reduce HIV-related stigma and a desire to be kept informed of the study's findings. Participation brought up some painful memories and issues for a number of individuals, with one interviewer noting, "*The survey touched upon some unresolved emotional issues... She cried when she thought about some of the things she has gone through within her life (abandonment, sexual abuse, etc.).*" Interviewers provided resources and referrals to mental

health providers, as needed, as well as for other needs that arose during the interview process (e.g., providing copies of the Declaration of Commitment on HIV/AIDS).

Interviewers recorded specific experiences with stigma that respondents shared. For example, one woman reported that being rejected by male partners was one of her main concerns after she tested positive. This actually happened to her three times after disclosing her status. According to the interviewer's notes,

*"Some of them directly told her that they were afraid. She got involved to educate them, but they still rejected her afterward. Her last rejection was three months ago. A man proposed to her and someone else disclosed her status and then he called off the marriage."*

Based on the interviewer notes and responses to the survey questions, a particular area in need of stigma interventions involves the criminal justice system. In the quantitative portion of the survey, several people who had been incarcerated mentioned stigmatizing behaviors while in custody. In this section of the survey, participants recounted specific instances. For example, one interviewee mentioned that

*"...when he was in prison the guards would sometimes point out the people who were positive – for fear that they may get spat on or bitten and people who were positive went on a different medication line."*

Another interviewee echoed these experiences, stating,

*"When he was in prison everyone that was positive went to medical care on a certain day. When it was time for medications there was a different line for people who were positive. The officers would sometimes call them out by saying all infectious diseases to go to medication line."*

Reflecting the broader study findings, several interviewers noted experiences that participants had with family members, friends, and members of their community which led them to feel stigmatized. For example, one woman told the interviewer that "She worried that her family will treat her differently. She has seen it happen with other family members." Another woman said that "Her religious community doesn't accept people who are HIV-positive and she fears that if they find out she will be treated badly. She...hasn't disclosed to anyone, not even her daughter."

Reflecting some of the earlier suggestions, one participant said that the survey should be given to people who are HIV negative. He thought it could be a good educational tool and might help with prevention efforts so that people could see the "intensity and protect themselves from contracting the virus."

As in other sections of the study, most experiences with stigma from health care providers had occurred more than 12 months prior. However, one participant recounted a relatively recent experience with stigma from a dental visit which caused her to cry during the interview. According to the interviewer's notes, the interviewee

*“...had an 8 o’clock appointment. However, many other individuals who came after her were received first. She questioned the delay and was told that, because of her HIV status, she will be seen last because, after seeing her, the room has to be sanitized.”*

In general, participants reported good experiences with health care providers and experiences like these were uncommon. Based on all of the available data from the study, the most common sources of stigma are family members/friends and the criminal justice system, particularly jails and prisons.

### **Recommendations**

The results from the New Jersey Stigma Index study suggest a number of possible policy and/or interventional recommendations. In no particular order, these include the following:

- **Allocate funding to address job training needs for PLHIV in New Jersey.** Participants in the study had low levels of education and half were unemployed at the time of their interview. These facts help to account for the high poverty levels and dependence on Medicaid seen in the majority of survey respondents. Although many respondents may be unable to work due to disability, the long-term improvements in health status and survival for PLHIV suggest that some may benefit from employment training programs. Given the uncertainty in the health care system and risks for roll-backs on Medicaid expansion under the ACA, improving individual sustainability may be an avenue for support for some people. However, since this will not be a viable option for everyone, the study’s findings clearly support an ongoing need for funding of the Ryan White HIV/AIDS Program and the AIDS Drug Distribution Program.
- **Improve rates of routine HIV screening and train primary care providers (PCPs) in HIV care.** Only 8% of participants stated that they had been diagnosed with HIV through routine HIV screening. Given the Centers for Disease Control and Prevention’s 2006 recommendation for routine HIV screening and its support from the United States Preventive Services Task Force in 2013 (Branson et al, 2006; Moyer, 2013), all PCPs should be prepared and able to provide HIV screening during office visits. Expanding routine primary care testing, or at least requiring primary care providers to offer patients materials on confidential HIV testing sites, would also address some of the problems and suggestions made by study participants related to the challenges of HIV testing. Enhancing HIV care within primary care practices can also help to address the stigma that some patients may feel when PCPs automatically refer them to outside care following an HIV diagnosis or when they are required to receive care from known HIV service providers because that is the only source of care available to them.
- **Eliminate laws and policies that criminalize HIV.** Fears of prosecution exacerbate internalized stigma and prevent disclosure and engagement in health care. Federal legislators and several states have introduced decriminalization measures. The Center for HIV Law & Policy (n.d.) provides an overview of New Jersey’s current policy environment and supports efforts to protect the rights and well-being of PLHIV. Supporting ongoing efforts to overturn New Jersey statutes that allow for criminal

prosecutions against PLHIV can have lasting impacts on improving the health and well-being of the entire community.

- **Provide additional funding to improve access to mental health care for all New Jerseyans and invest in programs to address the specific needs of PLHIV who suffer from mental health disorders.** Although this study cannot address the question of causality, the findings highlight the association between depression/anxiety and HIV infection. Those suffering from depression and other mental health disorders may be more likely to engage in behaviors that put them at risk for HIV infection, but infection with HIV and stigma associated with one's HIV-positive status clearly increase the risk of depression and isolation. Nationwide efforts to enhance mental health parity and to co-locate mental and physical health services show promise in addressing intersecting stigmas related to mental health disorders and facilitate entry into care.
- **Further study and interventions are needed to understand and address the problem of sleep disturbances among PLHIV.** Research indicates that up to 70% of PLHIV experience sleep disorders, with insomnia and obstructive sleep apnea among the most common causes (Taibi, 2013). Although this study did not identify the specific causes of sleep disturbances among study participants, the findings from the PROMIS-29 questions support the need for investing in efforts to improve sleep outcomes among New Jersey residents living with HIV.
- **Address stigma that occurs during incarceration.** Jails and prisons were the most common sites identified for stigmatizing behavior. The New Jersey Office of the Corrections Ombudsman investigates complaints regarding the “living conditions and treatment” of those who are incarcerated (Prison Policy Initiative, 2017). Improving HIV care in correctional settings has also been a priority for the Health Resources and Services Administration. PLHIV who face incarceration should be aware of these priority and resources available to them to ensure that they are treated with dignity within the criminal justice system and should expect proper discharge planning to enhance their linkage to care upon their release from custody.
- **Fund research on studies to better understand and address stigma among family members and friends of PLHIV.** The original goal of the Stigma Workgroup was to develop a manual to address HIV-related stigma within the health care system. However, the results of this study suggest that the primary problem of stigma lies with family members, friends, and other close community associates of PLHIV. Very little research has been conducted in the United States regarding stigma from close personal contacts of PLHIV and even less work has been done to develop interventions. This suggests an opportunity for groundbreaking work to identify the correlates and consequences of stigma within these interpersonal relationships. Addressing the stigma from these sources could dramatically improve the mental health of PLHIV as well, since it should improve systems of support.
- **Support the creation of a coalition of PLHIV to ensure follow-up on the study's findings and inform the development of interventions to combat HIV-related stigma.** Interviewers involved in the Stigma Index study reported to Mr. Peavy a desire

among themselves and many of the interviewees who participated in the study for the development of a statewide coalition of PLHIV, which would help to ensure the dissemination of the study's findings and action on relevant recommendations. Coalition participants could engage in educational campaigns, promote policy changes, inform the development of interventions to address HIV-related stigma in New Jersey, and participate in further research efforts. There was a strong desire to maintain the momentum and enthusiasm for eliminating stigma.

- **Convert the NJHPG's Stigma Workgroup into a standing committee to continue the work started with implementation of the Stigma Index.** Members of the New Jersey HIV/AIDS Planning Group's Issues Committee and Stigma Workgroup provided support to the data collection efforts and advice regarding the study's findings. Given the large number of recommendations arising from the study and the capacity for further analysis of the data (e.g., county-specific analyses to support Needs Assessments for funded agencies and analyses for specific subgroups of PLHIV), members of these groups have suggested the need to convert the Workgroup into a regular standing committee. The committee could work with State agencies, service providers, and the proposed Stigma Coalition to implement study recommendations, develop stigma interventions, and inform ongoing data analyses.

## Conclusions

New Jersey is the first state in the United States to implement the PLHIV Stigma Index statewide. Building on the State's robust HIV prevention and care infrastructure, the study was successful in mobilizing partnerships to achieve the goal of recruiting a broadly representative sample of PLHIV from throughout the state. The use of incentive payments was important both to recruitment efforts and to maintaining the enthusiasm of interviewers. Although the use of tablet computers or other computer-based methods for data collection might have saved time and costs in the long-term, and would likely be a necessary adaptation in geographically larger states wishing to undertake a similar statewide effort, the paper-based system proved effective for the current study. The success of the effort provided evidence of the ability to undertake a large-scale effort over a relatively short period of time. However, although the data appear to offer a good representation of PLHIV in New Jersey, recruitment efforts did not meet all targets for recruiting underserved groups, such as undocumented immigrants. Therefore, it is impossible to determine whether the findings are truly representative of all PLHIV in the state. However, the study offers a broad range of recommendations that, if undertaken, show promise in improving the lives and well-being of those living with, and affected by, HIV throughout New Jersey.

## References

- Branson, B. M., Handsfield, H. H., Lampe, M. A., Janssen, R. S., Taylor, A. W., Lyss, S. B., & Clark, J. E. (2006). Revised recommendations for HIV screening of adults, adolescents, and pregnant women in health-care settings. *Morbidity and Mortality Weekly Report*, 55(RR14), 1-17. doi: <http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5514a1.htm>
- DHSTS. (n.d.). About NJHPG: The New Jersey HIV/AIDS Planning Group. Retrieved from <http://hiv.rutgers.edu/njhpg/>.
- DHSTS. (2016). County and municipal HIV/AIDS statistics. Retrieved from <http://www.nj.gov/health/hivstdtb/hiv-aids/statmap.shtml>.
- Health Measures. (2017). PROMIS. Retrieved from <http://www.healthmeasures.net/explore-measurement-systems/promis>.
- IBM® Corporation. (2016). IBM® SPSS® Statistics for Mac, Version 24.0.0.0. Armonk, NY: IBM Corp.
- Logie, C. H., James, L., Tharao, W., & Loutfy, M. R. (2011). HIV, gender, race, sexual orientation, and sex work: A qualitative study of intersectional stigma experienced by HIV-positive women in Ontario, Canada. *PLoS Med* 8(11), e1001124. doi: <https://doi.org/10.1371/journal.pmed.1001124>
- Morris, N. S., MacLean, C. D., Chew, L. D., & Littenberg, B. (2006). The Single Item Literacy Screener: Evaluation of a brief instrument to identify limited reading ability. *BioMed Central Family Practice*, 7, 21. doi: 10.1186/1471-2296-7-21 Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1435902/>
- Moyer, V. A. (2013). Screening for HIV: U.S. Preventive Services Task Force recommendation statement. *Annals of Internal Medicine*, 159(1), 51-60. doi: 10.7326/0003-4819-159-1-201307020-00645
- NJHPG. (2012). The New Jersey HIV/AIDS Planning Group: 2012: A year in review. Retrieved from <http://hiv.rutgers.edu/wp-content/uploads/2016/05/2012YearinReview.pdf>.
- Office of the Assistant Secretary for Planning and Evaluation. (2017). Poverty guidelines. Retrieved from <https://aspe.hhs.gov/poverty-guidelines>.
- Prison Policy Initiative. (2017). Legal services for people in prison in New Jersey. <https://www.prisonpolicy.org/resources/legal/NJ/>
- Taibi, D. M. (2013). Sleep disturbances in persons living with HIV. *Journal of the Association of Nurses in AIDS Care*, 24(1 Supplement), S72-S85. doi: 10.1016/j.jana.2012.10.006. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3543776/>
- The Center for HIV Law & Policy. (n.d.). State HIV laws: New Jersey. Retrieved from <https://www.hivlawandpolicy.org/states/new-jersey>.

UNAIDS. (2007). *The greater involvement of people living with HIV (GIPA)*. Retrieved from [http://data.unaids.org/pub/briefingnote/2007/jc1299\\_policy\\_brief\\_gipa.pdf](http://data.unaids.org/pub/briefingnote/2007/jc1299_policy_brief_gipa.pdf).

UNAIDS. (2011). 2011 political declaration on human rights. Retrieved from <http://www.unaids.org/en/aboutunaids/unitednationsdeclarationsandgoals/2011highlevelmeetingonaids>.

UNAIDS. (2017). 90-90-90: An ambitious treatment target to help end the AIDS epidemic. Retrieved from <http://www.unaids.org/en/resources/documents/2017/90-90-90>.

UNAIDS, ICW Global, & Global Network of People Living with HIV. (2017). The People Living with HIV Stigma Index. Retrieved from <http://stigmaindex.org/>.

Table 1. Stigma Index Steering Committee Composition

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<b>Organization/Area</b>
New Jersey HIV/AIDS Planning Group
New Jersey Department of Health, Division of HIV, STD, and TB Services
International Community of Women Living with HIV – North America
Creole community
Southern Region provider
Northern Region provider
Non-Ryan White-funded provider
Southern Region consumer
Northern Region consumer
Central Region consumer
Rutgers University

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Table 2. Geographic and Demographic Distribution of PLHIV in New Jersey: 2014

<b>County</b>	<b>HIV Cases (12/31/13)</b>	<b>Survey Target (1% of Cases)</b>	<b>Surveys Completed</b>
Atlantic	1,487	15	15
Bergen	1,735	17	17
Burlington	804	8	2
Camden	1,865	19	22
Cape May	210	2	0
Cumberland	600	6	1
Essex	9,766	98	98
Gloucester	411	4	0
Hudson	5,081	51	51
Hunterdon	154	2	3
Mercer	1,512	15	14
Middlesex	2,098	21	21
Monmouth	1,895	19	21
Morris	827	8	7
Ocean	776	8	5
Passaic	2,584	26	26
Salem	170	2	2
Somerset	580	6	1
Sussex	163	2	2
Union	2,854	29	17
Warren	170	2	1
Unknown/Incarcerated	1,769	9	0
<b>Total</b>	<b>37,511</b>	<b>375</b>	<b>326</b>

Source: DHSTS, County and Municipal HIV/AIDS Statistics, 2013

Table 3. Demographic Characteristics of PLHIV in New Jersey: 2014

<b>Category</b>	<b>12/31/2013 Data (%)</b>	<b>Stigma Index Data (%)</b>
<b>Gender<sup>a</sup></b>		
Male	67	53.7
Female	33	39.0
Transgender	.	5.0
Other <sup>b</sup>	.	1.5
<b>Ages<sup>c</sup></b>		
< 25	3	4.6
25-34	10	9.8
35-44	17	14.7
45-54	36	35.0
>=55	34	35.3
<b>Ethnicity</b>		
Latino/Hispanic	26	17.5
African American/Black	51	68.4
Caucasian/White	21	11.3
Other	2	2.8
<b>Mode of Transmission<sup>d</sup></b>		
Male-to-male	28	.
Injection drug use	20	.
Heterosexual contact	38	.
Other/Unknown	14	.
<b>Years Since HIV Diagnosis</b>		
Within the last 5 years	15	10.7
5 to 10 years ago	19	11.3
10 to 15 years ago	22	15.0
15 to 20 years ago	22	16.6
More than 20 years ago	22	45.1
<b>Total Cases (Number)</b>	<b>37,511</b>	<b>326</b>

Source: DHSTS, County and Municipal HIV/AIDS Statistics, 2013

Notes: <sup>a</sup>DHSTS data include only male and female categories for 2013; <sup>b</sup>Other includes genderqueer and “other” responses; <sup>c</sup>Due to institutional review board oversight, data collection was limited to individuals aged 18 or older; <sup>d</sup>Mode of transmission is not explicitly asked in the PLHIV Stigma Index survey

Table 4. Special Populations Targeted for Recruitment

<b>Target Groups</b>
Sex workers
Undocumented immigrants
Formerly incarcerated
People with mental health disorders
People with substance abuse disorders
Gay men/bisexuals/MSM
People of transgender experience
Spanish-speakers
Haitians/Creoles
Other non-English speakers
Rural residents

Table 5. Relationship Status

<b>Status</b>	<b>Number</b>	<b>(%)</b>
Married	76	23.3
In a relationship but not living together	50	15.3
Single	170	52.1
Divorced/separated	14	4.3
Widowed	9	2.8

Table 6. Support Available

<b>Type of Support – Someone to...</b>	<b>All or Most of the Time (n)</b>	<b>(%)</b>
Listen when you need to talk	215	66.0
Take you to the doctor	175	53.6
Help you if you were confined to bed	157	48.2
Have a good time with	197	60.5
Show you love and affection	236	72.4
Give you information to help you understand a situation	228	69.9

Table 7. Educational Attainment

<b>Highest Level of Formal Education Completed</b>	<b>Number</b>	<b>(%)</b>
Primary school (grades K-8)	12	3.7
Secondary school (grades 9-12)	179	54.9
Some college/university	99	30.4
Graduated from college/university	19	5.8
Post-graduate degree (Master's or Doctorate)	11	3.4

Table 8. Employment Status

<b>Current Employment Status</b>	<b>Number</b>	<b>(%)</b>
Employed full-time	43	13.2
Employed part-time	37	11.3
Self employed	6	1.8
Doing casual work	11	3.4
Working under the table	19	5.8
Unemployed and not looking	165	50.6
Looking for work	47	14.4

Note: Respondents could select multiple categories

Table 9. Health Insurance Coverage

<b>Group</b>	<b>Number</b>	<b>(%)</b>
Medicaid/FamilyCare	196	60.1
Medicare	108	33.1
Public Insurance – Other	6	1.8
Obamacare/Marketplace/ACA	16	4.9
Employer Sponsored	25	7.7
Private – Other	11	3.4
Premium Assistance from Ryan White	10	3.1
Ryan White Only	30	9.2
Other Coverage	30	9.2
Uninsured	15	4.6

Note: Respondents could select multiple categories

Table 10. Group Identification

<b>Group</b>	<b>Number</b>	<b>(%)</b>
Men who have sex with men	102	31.3
Gay/Lesbian	87	26.7
Bisexual	48	14.9
Transgender	16	4.9
Sex Worker	51	15.6
Injection Drug User	77	23.6
Homeless	109	33.4
Refugee/Asylum Seeker	1	0.3
Internally Displaced Person	13	4.0
Heterosexual	159	48.8
Migrant Worker	2	0.6
Formerly Incarcerated	102	31.3
Mentally Ill	111	34.0
Living in Poverty	94	28.8
None of the Above	10	3.1

Note: Respondents could select multiple categories

Table 11. PROMIS-29

<b>Domain</b>	<b>Mean</b>	<b>Std. Deviation</b>
Physical Function	6.9	3.86
Anxiety	9.5	4.03
Depression	8.7	4.12
Fatigue	9.8	3.92
Sleep Disturbance	12.1	4.08
Ability to Participate in Social Roles/Activities	8.6	3.92
Pain Interference	9.5	4.91
Pain Scale	4.6	3.2
Total Score	65.4	20.86

Table 12. Experiences with Stigma and Discrimination

<b>Experienced in the Last 12 Months</b>	<b>Percentage Stating</b>			
	<b>Never</b>	<b>Once</b>	<b>A Few Times</b>	<b>Often</b>
Excluded from social gatherings	69.3	8.0	18.1	3.7
Excluded from religious activities	87.4	2.8	4.9	3.4
Excluded from family activities	78.5	3.4	9.8	5.5
Gossiped about	38.0	9.2	34.7	16.3
Verbally insulted/harassed/threatened	59.8	13.5	21.5	4.9
Physically harassed/threatened	80.4	7.7	9.5	1.5
Physically assaulted	86.8	6.1	4.6	0.9
HIV status used against you by partner	82.2	5.8	8.3	1.5
Experienced sexual rejection	78.5	6.1	11.7	2.8
Discriminated against by other PLHIV	77.3	5.5	14.4	2.8
Discriminated against by ASO worker <sup>a</sup>	84.4	7.1	7.1	1.2
Family experienced discrimination	76.4	4.6	4.9	1.5
Forced to change residence	79.8	9.5	7.4	2.5
Lost a job or other source of income <sup>b</sup>	66.3	7.4	2.8	0
Nature of work changed <sup>b</sup>	69.0	0.9	1.2	0
Dismissed from educational institution	83.1	2.8	0.9	0.3
Children dismissed from school <sup>c</sup>	58.9	0.9	0.9	0.3
Denied health services	80.7	4.0	4.6	0.3

Note: <sup>a</sup>ASO – HIV/AIDS Service Organization; <sup>b</sup>Only asked of respondents who have had a source of income in the past 12 months; <sup>c</sup>Only asked of respondents with children

Table 13. Stigma/Discrimination in Health Care Settings

<b>Provider Type</b>	<b>Number</b>	<b>(%)</b>
Clinic Administrator	9	2.8
Receptionist	18	5.5
Medical assistant	9	2.8
Physician	20	6.1
Nurse Practitioner	8	2.5
Physician's assistant	6	1.8
Nurse	10	3.1
Emergency Department staff	17	5.2
Staff at Obstetrics/Gynecology practice	3	0.9
Pharmacist	6	1.8
Dentist	14	4.3
Dental hygienist	9	2.8
Social worker	10	3.1
Other case worker	10	3.1
Other health care provider	11	3.4

Note: Respondents could select multiple categories

Table 14. Reason for Stigma/Discrimination

<b>Reason</b>	<b>Number</b>	<b>(%)</b>
People are afraid of getting infecting with HIV from me	101	31.0
Fear of being infected through casual contact	127	39.0
People think HIV is shameful and don't want to associate with me	100	30.7
Religious beliefs or "moral" judgments	39	12.0
People disapprove of my lifestyle or behavior	72	22.1
I look sick with symptoms associated with HIV	15	4.6
I don't know why	59	18.1
Some other reason	14	4.3

Note: Respondents could select multiple categories

Table 15. Reason for Stigma/Discrimination Other than HIV Status

<b>Group</b>	<b>Number</b>	<b>(%)</b>
Gay/Man who has sex with men/lesbian	85	26.1
Bisexual	25	7.7
Transgender person	11	3.4
Sex Worker	33	10.1
Injection Drug User	47	14.4
Refugee/Asylum Seeker	1	0.3
Internally Displaced Person	2	0.6
Native American	11	3.4
Migrant Worker	2	0.6
Formerly incarcerated	61	18.7
Immigrant	11	3.4
Person with a disability	40	12.3
Unemployed	61	18.7
Member of ethnic minority group	52	16.0
Member of religious minority group	12	3.7
Homeless	61	18.7
Person with diagnosed mental illness	57	17.5
Person living in poverty	53	16.3
None of the above/other	56	17.2

Note: Respondents could select multiple categories

Table 16. Sequelae of External Stigma/Discrimination

<b>Results of Exposure to External Stigma</b>	<b>Number</b>	<b>(%)</b>
Depression	171	52.5
Anxiety	148	45.4
Income loss	53	16.3
Withdrawal from family/friends	130	39.9
Withdrawal from faith-based or spiritual support	49	15.0
Avoiding health care	48	14.7
Avoiding social support	62	19.0
Missed days at work/school	31	9.5
Skipped doses of medications	76	23.3
Increased drug/alcohol intake	71	21.8
Reduced exercise/physical activity/sleep	93	28.5
Other effects	11	3.4

Note: Respondents could select multiple categories

Table 17. Feelings Associated with Internal Stigma

<b>Feelings Experienced in the Past 12 Months</b>	<b>Number</b>	<b>(%)</b>
Ashamed	119	36.5
Guilty	87	26.7
Blame myself	175	53.7
Blame others	80	24.5
Low self-esteem	127	39.0
Feel I should be punished	25	7.7
Suicidal	31	9.5
Angry	154	47.2

Table 18. Behaviors Associated with Internal Stigma

<b>Behaviors Experienced in the Past 12 Months</b>	<b>Number</b>	<b>(%)</b>
Chosen not to attend social gatherings	75	23.0
Isolated myself from family/friends	105	32.2
Made the decision to stop working	39	12.0
Decided not to apply for a job or promotion	36	11.0
Withdrew from or did not take an opportunity for education	32	9.8
Decided not to get married	43	13.2
Decided not to have sex	85	26.1
Decided not to have (more) children	84	25.8
Avoided going to a local clinic or doctor when I needed to	38	11.7
Avoided going to a hospital when I needed to	33	10.1
Decided not to participate in social media	56	17.2
Decided not to share my status with someone who might support me	99	30.4

Table 19. Fears Associated with Internal Stigma

<b>Fears Associated with HIV Status in the Past 12 Months</b>	<b>Number</b>	<b>(%)</b>
Being gossiped about	164	50.3
Being verbally insulted/harassed/threatened	116	35.6
Being physically insulted/harassed/threatened	81	24.8
Being physically assaulted	71	21.8
Being denied health care	62	19.0
Having HIV status shared without consent online or via social media	134	41.1
Someone would not want to be sexually intimate with you	147	45.1

Table 20. Reaction to HIV Prevention Campaign

<b>Emotional Reaction</b>	<b>Number</b>	<b>(%)</b>
Empowered	147	45.1
Stigmatized	29	8.9
Frightened	17	5.2
Shamed	21	6.4
Encouraged	164	50.3
Other reaction	17	5.2

Note: Respondents could select multiple categories

Table 21. Awareness of Organizations or Groups that Support PLHIV

<b>Organization Type</b>	<b>Number</b>	<b>(%)</b>
PLHIV support group	237	72.7
Network of PLHIV	168	51.5
Local AIDS Service Organization	224	68.7
Faith-based organization	73	22.4
Legal practice	79	24.2
Legal practice specializing in HIV cases	104	31.9
Human rights organization	82	25.2
National non-profit organization	77	23.6
Nationals HIV council or committee	77	23.6
International non-governmental organization	21	6.4
United Nations organization	8	2.5
LGBT rights organization	97	29.8
Civil rights organization	51	15.6
Other type of organization	25	7.7

Note: Respondents could select multiple categories

Table 22. Feelings of Empowerment to Influence Decision-Making

<b>Area of Influence</b>	<b>Number</b>	<b>(%)</b>
Legal matters affecting PLHIV	130	39.9
Local government policies affecting PLHIV	113	34.7
Local projects intended to benefit PLHIV	150	46.0
National government policies affecting PLHIV	89	27.3
National programs/projects intended to benefit PLHIV	103	31.6
International agreements/treaties	35	10.7
None of these things	120	36.8

Table 23. Activities that Should be Undertaken to Support PLHIV

<b>Activities Endorsed</b>
Advocating for the rights of PLHIV
Providing emotional/physical/referral support for PLHIV
Advocating for the rights of marginalized groups (e.g., immigrants, transgender people)
Educating PLHIV about living with HIV
Raising awareness and knowledge of the public about HIV
Building networks of PLHIV and supporting advocacy to bring about change
Addressing poverty, homelessness, and trauma among PLHIV
Other activities

Table 24. Reason for Testing at Time of HIV Diagnosis

<b>Reason for Testing</b>	<b>Number</b>	<b>(%)</b>
Employment	8	2.5
Pregnant or delivery	19	5.8
Prepare for marriage/sexual relationship	13	4.0
Referred by clinic for sexually transmitted infections	38	11.7
Referred due to suspected HIV-related symptoms	52	16.0
Family member tested positive	37	11.3
Illness or death of family member	18	5.5
Just wanted to know	112	34.4
Part of routine check-up or surgical procedure	27	8.3
Encouraged by family member/friend	46	14.1
Military induction or service	1	0.3
In relation to incarceration	21	6.4
Health or life insurance coverage	6	1.8
Immigration purposes	0	0.0
Other	87	26.7

Note: Respondents could select multiple categories

Table 25. Prior HIV Testing

<b>Ever Taken HIV Test Prior to Test at Diagnosis</b>	<b>Number</b>	<b>(%)</b>
Yes, one time and the result was negative	63	19.3
Yes, many times and the results were negative	60	18.4
Yes, but I did not get my results	13	4.0
No, this was my first HIV test	176	54.0

Table 26. Decision for HIV Testing

<b>Decision to be Tested Up to You</b>	<b>Number</b>	<b>(%)</b>
Yes, I took the decision myself	229	70.2
I took the decision, but it was under pressure from others	26	8.0
I was made to take an HIV test	21	6.4
I was tested without my knowledge and informed afterward	21	6.4

Table 27. HIV Counseling

<b>Counseling Received When Tested</b>	<b>Number</b>	<b>(%)</b>
Pre- and post-test counseling	114	35.0
Pre-test counseling only	12	3.7
Post-test counseling only	59	18.1
No counseling	98	30.1

Table 28. How Long Waited to be Tested

<b>Time to Test</b>	<b>Number</b>	<b>(%)</b>
0 to 3 months	202	62.0
4 to 6 months	38	11.7
7 to 12 months	22	6.7
1 to 2 years	18	5.5
2 to 5 years	15	4.6
More than 5 years	12	3.7

Table 29. Fears Related to Consequences of Testing Positive for HIV

<b>Fear Cited</b>	<b>Number</b>	<b>(%)</b>
Job loss or removal from school program	47	14.4
Shunned by family/friends	191	58.6
Partner would be physically violent	45	13.8
Other family would be physically violent	33	10.1
Members of community would be physically violent	42	12.9
Partner would leave	77	23.6
Children would be taken away	22	6.7
Forced to terminate pregnancy	12	3.7
Children would be treated badly	42	12.9
Would not be able to get married	73	22.4
Forced to leave my home or community	50	15.3
Legal authorities would bring criminal charges against me	27	8.3
People would find out about my behaviors related to HIV infection	83	25.5
People would think I am promiscuous/a sex worker/MSM/IV drug user	112	34.4
Other fear	32	9.8

Note: Respondents could select multiple categories

Table 30. How Long Waited to Obtain Health Care After Diagnosis

<b>Time to Obtain Care</b>	<b>Number</b>	<b>(%)</b>
0 to 3 months	216	66.3
4 to 6 months	37	11.3
7 to 12 months	19	5.8
1 to 2 years	14	4.3
2 to 5 years	14	4.3
More than 5 years	17	5.2
I have not yet seen a health care provider for my HIV diagnosis	1	0.3

Table 31. Reasonableness of Behaviors Related to HIV-Positive Status

<b>How Reasonable is it for a Person Who Otherwise Feels Healthy to Avoid...</b>	<b>Very (%)</b>	<b>Somewhat (%)</b>	<b>Not at All (%)</b>
HIV testing out of fear of being prosecuted if test is positive	19.9	33.1	46.0
Disclosing status to current sexual partner for fear of prosecution	25.8	29.4	43.9
HIV treatment for fear that others might find out and press charges	25.2	26.7	47.2

Table 32. Disclosure of HIV Status

<b>Person or Group</b>	<b>Who First Informed Out About Your HIV Status (%)</b>				
	<b>I told them</b>	<b>Someone else <i>with</i> consent</b>	<b>Someone else <i>without</i> consent</b>	<b>They don't know my HIV status</b>	<b>Not Applicable</b>
Husband/wife/partner	62.9	0.3	3.4	2.8	25.8
Other adult family members	68.7	3.4	12.6	6.4	7.7
Children in your family	42.9	2.5	6.1	15.0	27.3
Friends/neighbors	47.9	2.5	10.1	17.5	17.5
Other PLHIV	73.6	4.3	3.7	4.0	11.7
Co-workers	18.4	0.0	2.5	22.1	52.5
Employer(s)	15.3	0.3	0.9	23.3	54.9
Clients	8.9	0.3	0.0	11.7	70.9
Injecting drug partners	11.0	0.3	1.8	6.1	72.4
Religious leaders	23.9	1.2	0.9	12.9	54.3
Community leaders	15.3	0.9	0.6	18.4	54.0
Health care workers	78.8	5.5	0.9	3.1	6.7
Social workers/counselors	81.0	5.8	0.3	2.5	6.4
Teachers	6.4	0.3	0.3	10.1	74.5
Government officials	9.5	0.6	0.0	11.6	70.9
The media	4.3	0.0	1.2	11.3	74.8
Prison officers	6.7	0.9	3.4	7.1	73.9

Table 33. Reactions to Disclosure of HIV Status

Person or Group	Reactions (%)					
	Very Discriminatory	Discriminatory	No Different	Supportive	Very Supportive	Not Applicable
Husband/wife/partner	3.7	5.2	12.6	19.3	28.2	27.9
Other adult family members	6.1	12.3	12.6	24.8	26.4	15.2
Children in your family	2.5	3.1	14.4	16.0	20.9	40.5
Friends/neighbors	1.8	8.9	12.6	25.2	17.5	31.6
Other PLHIV	0.6	2.1	12.9	37.4	32.8	11.7
Co-workers	0.3	1.8	4.3	9.2	6.1	74.5
Employer(s)	1.8	0.9	4.9	6.1	5.8	77.3
Clients	0.9	0.6	2.5	3.1	1.8	84.7
Injecting drug partners	1.2	0.9	5.8	4.0	1.2	81.6
Religious leaders	1.8	1.5	4.0	7.1	13.5	66.9
Community leaders	1.2	1.5	4.0	6.1	8.0	69.9
Health care workers	2.5	2.1	9.8	23.0	39.9	15.0
Social workers/counselors	2.8	1.2	8.0	28.8	42.0	13.2
Teachers	0.6	0.3	1.5	1.5	4.3	86.5
Government officials	0.9	1.2	1.8	1.5	4.6	84.0
The media	2.1	1.2	1.5	1.2	1.5	86.5
ASO Staff	2.5	0.6	8.9	23.0	44.5	16.9
Prison officers	3.1	3.7	2.8	1.2	0.9	82.5

Notes: ASO – AIDS Service Organization

Table 34. General Health Status

<b>Current Self-Rated Health</b>	<b>Number</b>	<b>(%)</b>
Excellent	80	24.5
Very good	79	24.2
Good	82	25.2
Fair	72	22.1
Poor	12	3.7

Table 35. Frequency of HIV-Related Care

<b>Time Elapsed</b>	<b>How Long Ago Since Last</b>	
	<b>Office Visit</b>	<b>Lab Test</b>
	<b>(%)</b>	<b>(%)</b>
Within the last 3 months	85.9	82.2
Within the last 6 months	10.1	13.2
Within the last year	2.5	2.1
More than 1 year ago	0.6	0.6
I have never had this done	0.3	0.6
I don't know	0.6	0.6

Table 36. Most Recent Viral Load

<b>Result</b>	<b>Number</b>	<b>(%)</b>
Undetectable or less than 50 copies	246	75.5
50 to 10,000 copies	38	11.7
10,000 to 100,000 copies	12	3.7
More than 100,000 copies	6	1.8
I don't know	21	6.4

Table 37. Most Recent CD4 Count

<b>Result</b>	<b>Number</b>	<b>(%)</b>
More than 1,000	68	20.9
500 to 1,000	114	35.0
350 to 500	40	12.3
200 to 350	28	8.6
Under 200	22	6.7
I don't know	51	15.6

Table 38. Communication Regarding Health Issues

<b>Item</b>	<b>Number</b>	<b>(%)</b>
Have had a constructive discussion with provider about treatment options (last 12 months)	265	81.3
Feel supported by health care providers to make decisions for yourself	307	94.2
Health care providers explains things in a way that is helpful	298	91.4
Understand the details of your treatment regimen	300	92.0
Feel you have adequate support to maintain your treatment regimen	297	91.1
Have had a constructive discussion with a health care professional about adherence (last 12 months)	254	77.9
Have had a constructive discussion with a health care professional about other subjects (last 12 months)	225	69.0

Table 39. Efficacy of Health Care

<b>Item</b>	<b>Very Much (%)</b>	<b>A Little (%)</b>	<b>Not at All (%)</b>	<b>NA (%)</b>
My treatment regimen is a good fit for me and my life	82.5	7.7	2.5	3.4
My health care providers understand and support me and people like me	86.2	8.9	0.3	0.9
My health care providers give me exactly the kinds of care that I need	84.7	8.9	1.5	1.2
My case managers/social workers understand and support me and people like me	82.8	9.5	0.3	3.4
My case managers/social workers give me exactly the kinds of care that I need	79.8	11.7	0.9	4.0

Notes: NA – Not applicable

Table 40. Stigma and Discrimination Faced While Incarcerated (N = 76)

<b>Experiences Due to HIV Status</b>	<b>Number</b>	<b>(%)</b>
Required to see health care workers at different time/place than others	24	31.6
Names of medications announced loudly	13	17.1
Diagnosis announced loudly when picking up medications	3	3.9
Had to pay for medications	5	6.6
Received partial doses of HIV medications that required return visits	14	18.4
Did not receive specialty care	30	39.5
Did not receive regular CD4/viral load testing	30	39.5
Did not receive 30 days of medications upon release	33	43.4
Was not connected to health services after release	33	43.4
Was segregated in my living quarters	4	5.3
Not allowed to work in food service	23	30.3
Denied access to education	1	1.3
Denied access to job training	3	3.9
Had to meet visitors in different place than regular visiting area	1	1.3
HIV status was disclosed by health care workers	11	14.5
HIV status was disclosed by prison officials	20	26.3
HIV status was disclosed by guards	21	27.6
HIV status was disclosed by other people who were incarcerated	25	32.9
Sentencing was enhanced	1	1.3

Figure 1. Study Organizational Chart



