Findings from the People Living with HIV Stigma Index Survey

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What is Stigma?

What is stigma?

- Stigma (noun)
  1. a mark of disgrace associated with a particular circumstance, quality, or person

From: http://oxforddictionaries.com/definition/english/stigma Accessed on: 09/18/12
Stigma, Stereotypes, Prejudice, Discrimination

- Stigma – a label or judgment
- Stereotype – generalized belief
- Prejudice – a negative attitude
- Discrimination – behavior that excludes
Types of Stigma

• Anticipated Stigma — a belief that discrimination may occur

• Associated Stigma — stigma against people who work or associate with people living with HIV

• Experienced/Enacted Stigma — discrimination experienced due to real or perceived seropositive status

• Internalized Stigma — thoughts/behaviors stemming from one’s own negative perceptions of oneself

• Intersecting Stigma — stigma associated with other social categories associated with HIV
About the People Living with HIV (PLHIV) Stigma Index

- Both a data collection tool and an intervention
  - Measures and detects trends
  - Advocates on key barriers
- Began in 2008
  - More than 90 countries have completed the study so far
  - Translated into 54 languages
- Supports Greater Involvement of People living with HIV/AIDS (GIPA)
  - More than 2,000 PLHIV have been trained as interviewers
  - More than 100,000 PLHIV have been interviewed
- Questionnaire currently being revised and updated

http://www.stigmaindex.org/
Questionnaire Explores 10 Key Areas

1) Experiences of stigma and discrimination and their causes
2) Access to work and services
3) Internal stigma
4) Rights, laws, and policies
5) Effecting change
6) HIV testing
7) Disclosure and confidentiality
8) Treatment
9) Having children
10) Problems and challenges

→ Questions added to address local context
Three Unique Features of the Process

• Involvement of PLHIV
  • Development of the Index
  • Interviewing
  • Analysis
  • Advocacy

• ‘Side by side’ interviewing
  • PLHIV trained as interviews in empathetic role

• Proactive system of referrals
  • Interviewers trained to elicit referral needs of interviewees
  • Resource packets available for those needing referral services
• 33 interviewers recruited
  • PLHIV from all regions of the state

• 371 interviews completed overall
  • 1% sample of adults (18+) living with HIV by county
  • Inclusive of the diversity of PLHIV in New Jersey

• Targeted recruitment for underrepresented groups
## Demographics of Participants vs. State Data

<table>
<thead>
<tr>
<th>Category</th>
<th>12/31/2013 Data (%)</th>
<th>Stigma Index Data (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>67</td>
<td>53.6</td>
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<tr>
<td>Female</td>
<td>33</td>
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<td>Transgender</td>
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<td>Other</td>
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<td>1.3</td>
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<tr>
<td><strong>Ages</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 25</td>
<td>3</td>
<td>5.1</td>
</tr>
<tr>
<td>25 to 34</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>35 to 44</td>
<td>17</td>
<td>15.1</td>
</tr>
<tr>
<td>45 to 54</td>
<td>36</td>
<td>33.7</td>
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<tr>
<td>&gt;= 55</td>
<td>34</td>
<td>35.6</td>
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<tr>
<td><strong>Ethnicity</strong></td>
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<tr>
<td>Latino</td>
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<td>18.1</td>
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<tr>
<td>White</td>
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<td>16.7</td>
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<td>Other</td>
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<td>2.4</td>
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<td><strong>Years Since HIV Diagnosis</strong></td>
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<tr>
<td>Within the last 5 years</td>
<td>15</td>
<td>11.3</td>
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<tr>
<td>5 to 10 years ago</td>
<td>19</td>
<td>12.9</td>
</tr>
<tr>
<td>20 to 15 years ago</td>
<td>22</td>
<td>14.8</td>
</tr>
<tr>
<td>15 to 20 years ago</td>
<td>22</td>
<td>15.6</td>
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<tr>
<td>More than 20 years ago</td>
<td>22</td>
<td>44.2</td>
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<tr>
<td><strong>Total Cases (Number)</strong></td>
<td>37,511</td>
<td>371</td>
</tr>
</tbody>
</table>
Sources of Vulnerability

• Participants were economically vulnerable
  • 60% had completed a high school degree or less
  • 64% were unemployed
  • 60% were on Medicaid

• Mental health problems due to stigma were common
  • 50% experienced depression
  • 43% suffered from anxiety
  • 38% had withdrawn from family and/or friends
Sources of Stigma

• The most frequently cited sources of stigma were family and friends

• Gossip was the most common type of external stigma experienced by participants
  • 61% had ever been gossiped about
  • 51% feared being gossiped about

• Participants commonly experience internal stigma
  • 55% blame themselves for their HIV status
  • 40% experience low self-esteem
  • 38% feel ashamed
Consumer Stigma Coalition

• Included as one of the recommendations from the project’s White Paper
• Comprised of interviewers and interviewees who participated in the study
• Goals are to:
  • Ensure that the study’s findings are disseminated
  • Assist in the development and testing of interventions to reduce HIV-related stigma
  • Inform statewide informational campaigns to counter misinformation and myths about HIV
  • Maintain the momentum and enthusiasm for eliminating HIV-related stigma
NJHPG Stigma Committee Priorities

• Distribution of the study’s findings
  • Academic publications
  • Forthcoming book chapter
  • Abstract submitted to AIDS 2018

• Research on stigma interventions targeting family members/friends/community
  • Bystander training
  • Story Corps

• Public information campaigns to (re)educate members of the community about HIV
  • Modes of transmission
  • Importance of routine testing
  • Available methods of prevention and treatment (Undetectable = Untransmittable)
Questions?
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