

SPOTLIGHTING SHADOWS

AN INDEX TO MEASURE STIGMA DEVELOPED AND IMPLEMENTED BY PEOPLE LIVING WITH HIV

“As an activist and as practitioner in the Dominican Republic, I want to use the findings from the index to make definite recommendations for policies”

DULCE ALMONTE, REDOVIIH JUNE 2008

“People don’t know what their rights are—they don’t know that their rights are not being enforced. It has been empowering to talk to people about their rights. We have new friends, new partners, and my personal hope is that this will help us eliminate stigma”

INDEX RESEARCHER, JUNE 2008



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BACKUP Initiative



Stigma and discrimination continue to pose a critical barrier to achieving universal access to HIV related prevention, treatment, care and support. Much of what we know about the stigma attached to HIV, and resulting discrimination, is anecdotal or fragmented, and does not include the perspectives of people living with HIV. **The People Living with HIV Stigma Index** will fill this gap in our global understanding, and build an evidence base to inform policy and practice.

The People Living with HIV Stigma Index

The Index is a new research initiative to measure stigma, by and for people living with HIV. The index is the product of an ongoing partnership between two networks of people living with HIV (GNP+ and ICW), UNAIDS and IPPF. The index was piloted in 2006 in five countries (Kenya, Lesotho, Trinidad and Tobago, India and South Africa) and developed in collaboration with activists, research experts and human rights champions around the world.

In the Dominican Republic

The Dominican Republic is the first country where the index is being implemented. A team of researchers from two of the national networks of people living with HIV (ASOLSIDA and REDOVIIH) have been working alongside Profamilia (the national family planning association) to carry out the research. To date almost 900 interviews have been completed, in four geographical regions covering 20 of the 32 provinces. In addition to asking questions about stigma, discrimination and living with HIV the index has also included a special focus on women, gender violence and young girls.

Initial findings

The findings from implementing the index in the Dominican Republic will be collated and analysed in September 2008. Initial lessons learnt include:

- **Joining policies and practice:** From the process of conducting the interviews, the interviewers have valued meeting new people in the field and sharing information about rights, laws and policies that support people living with HIV
- **Forging partnerships:** Working with the two network leaders (ASOLSIDA and REDOVIIH) as interviewers, team leaders and quality controllers has strengthened the research process and highlights the importance of partnerships that cut across all levels of implementing the index
- **Raising awareness about HIV stigma:** The interviewers found that people often did not consider that they had been ‘stigmatized’ or ‘discriminated’ against because of their HIV positive status. For example they may answer ‘no’ to a question asking them if they have experienced stigma, yet then relate a story which vividly indicates that they have
- **Supporting PLHIV:** The research shows that support for the interviewers is just as important as supervision to assure the quality and sensitivity of the research process
- **Unearthing sensitive issues:** The process of referral and follow-up is very important after each interview, but this can be difficult where the interviews are anonymous and confidentiality has been assured
- **Linking qualitative and quantitative research:** The index is valuable tool in documenting the experiences of stigma and discrimination faced by many, yet the individual stories also illuminated the realities of people living with HIV in the Dominican Republic. Qualitative case studies and life stories can compliment the findings of the index and strengthen the research process and outcomes

Next steps

The findings of the research will be disseminated and used to promote debate and advocate for effective policy and programmatic change. Specific areas include:

- Inform and influence the national review of law 5593 (a national law to protect the rights of people living with HIV) in the Dominican Republic. Key advocacy points include:
 - More effective communication, education and outreach about the law so that people living with HIV know their rights
 - Increased advocacy and public awareness about the law so that the general public is aware of the legal institutions in place to protect the rights of people living with HIV
 - Inform policy and practice relating to rights, confidentiality and testing, especially for young people
- Incorporate findings into the Pan American Health Organization (PAHO) review of key issues concerning barriers to accessing HIV services and care in Latin America
- Promote the human rights of people living with HIV, for example advocating against the forced sterilization of women who are diagnosed HIV positive
- Improve the outreach and services provided by Profamilia in meeting the needs of people living with HIV and integrating HIV with sexual and reproductive health services

The index results and follow-up case studies will continue to advocate for evidence based policy and practice that is grounded in the real experiences and perspectives of people living with HIV.

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