People Living with HIV Stigma Index
Sri Lanka

November 2010

THE PEOPLE
LIVING
WITH HIV
STIGMA
INDEX

IPPF International Planned Parenthood Federation

UNAIDS
JOINT UNITED NATIONS PROGRAMME ON HIV/AIDS
UNHCR UNICEF WFP UNDP UNFPA
UNODC ILO UNESCO WHO WORLD BANK

International Community of Women living with HIV/AIDS (ICW)

NATIONAL STD/AIDS CONTROL PROGRAMME

LANKA+

GNP+ GLOBAL NETWORK OF PEOPLE LIVING WITH HIV

Positive Hopes ALLIANCE
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Positive Women's Network

fpa SRI LANKA
Pioneer in Reproductive Health

PREFACE

It is our pleasure as networks of people living with HIV to partner with the Stigma Index research. This important research, for the first time, analyzes levels of stigma and discrimination from the perspective of people living with HIV in Sri Lanka. **We conducted this research for our own people.** They were comfortable discussing their experiences with us, because they knew that we understood.

A number of incidents of both physical and psychological harassment due to HIV status have been reported in the recent past. We are pleased that there have been timely interventions to reduce such incidents in the future, but more needs to be done if people living with HIV are to live positive and dignified lives.

The strategic information generated by this report lays the foundation and outlines the need for policy and practice that ensures our legal and human rights. We, as representatives of people living with HIV in Sri Lanka expect that the recommendations of this report be seriously considered and also integrated into future national strategic plans that deal with HIV & AIDS in Sri Lanka.

P.S. Rodrigo
Shereen Rodrigo
President,
Lanka+

Princey
Princey Mangalika
Director,
Positive Women's Network

S. Jayaratha
Sunanda Jayarathne
General Secretary,
Positive Hopes Alliance

FOREWORD

It gives us great pleasure to share with you the results of the Stigma Index Report and findings.

At the heart of human rights is human dignity. And central to human dignity is a life free from stigma, discrimination and a commitment to upholding everyone's human rights. This means honouring the Declaration of Commitment on HIV/AIDS promulgated by the General Assembly of the United Nations and to which Sri Lanka is a signatory.

The Stigma Index Report provides, for the first time, an important insight into the manner of injustice found against people who are HIV positive in Sri Lanka. It not only reveals that direct and visible injustice occurs, such as verbal harassment, domestic abuse, intimate partner violence as well as lost employment opportunities, but also finds significant levels of invisible or structural injustice exists.

The many types of injustice found to be perpetrated against people infected with the virus or against people from communities most vulnerable to HIV and AIDS means that their human rights and the opportunities afforded them by such rights are gravely diminished. It means that opportunities for people with HIV and AIDS to confidently live the same full and rewarding lives as those less affected people are unfairly curtailed. Key amongst the many findings of the Sri Lankan Stigma Index Report are the high levels of "internalised stigma" experienced by people who are infected or affected by HIV and the "corresponding decisions" they make in the face of the many structural or invisible societal barriers in Sri Lankan society. Unfair stereotyping of people with HIV is linked to prejudicial attitudes and there is a need to strengthen avenues through which remedies can be sought by those who have been discriminated against.

As the report asserts, "If the Stigma Index points to anything, it points to the need for positive living – how to live positive, productive and full lives with HIV – in Sri Lanka."

Finally we commend the work of the community of people living with HIV in Sri Lanka, who have tirelessly researched and compiled this report. We are honoured to be involved in delivering its findings.

Dr Nimal Edirisinghe
Director,
National STI & AIDS Control Programme
Sri Lanka

Mr Gamini Wanasekara
Executive Director,
Family Planning Association
Sri Lanka

Mr David Bridger
UNAIDS Country Coordinator
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ACKNOWLEDGEMENTS

The successful implementation of the People Living with HIV Stigma Index in Sri Lanka would not have been possible without the support of **Lanka+** and **Positive Hopes Alliance** (two networks of people living with HIV in Sri Lanka), **UNAIDS** in Colombo, and the **Family Planning Association of Sri Lanka**.

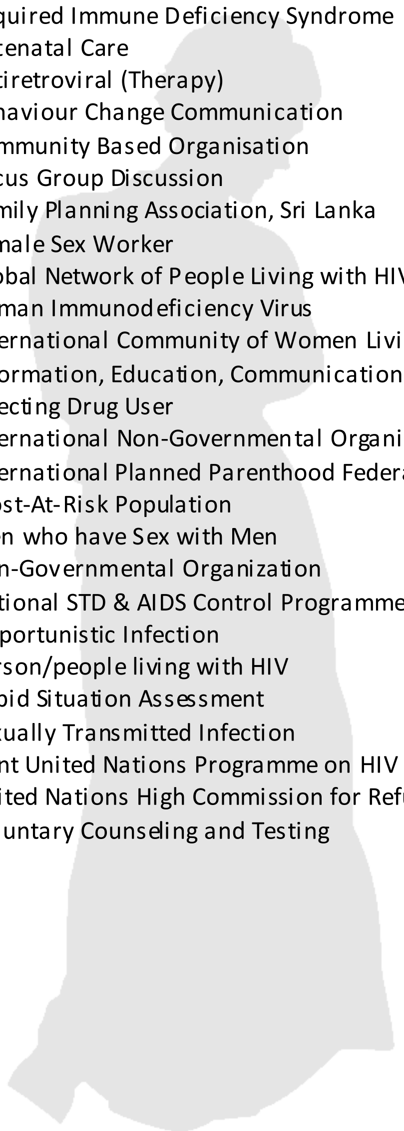
We would also like to thank the **National STD & AIDS Control Programme** for technical support with the translation of the questionnaire, and **International Planned Parenthood Federation UK and India**, for technical support and advice during the implementation and analysis phases.

We are especially grateful for the **research team of people living with HIV** that diligently performed the interviews, sometimes under arduous conditions, and similarly our gratitude extends to **all those people living with HIV** who participated in the Stigma Index study.

Finally we would like to thank the team from **Grassroots Development Consultants** for help with facilitating the training programme of the Stigma Index interview team, analysis of the gathered data, and for producing this report.

Hans Billimoria
National Research Consultant
People Living with HIV Stigma Index Sri Lanka

ACRONYMS



AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Care
ARV (ART)	Antiretroviral (Therapy)
BCC	Behaviour Change Communication
CBO	Community Based Organisation
FGD	Focus Group Discussion
FPASL	Family Planning Association, Sri Lanka
FSW	Female Sex Worker
GNP+	Global Network of People Living with HIV/AIDS
HIV	Human Immunodeficiency Virus
ICW	International Community of Women Living with HIV/AIDS
IEC	Information, Education, Communication
IDU	Injecting Drug User
INGO	International Non-Governmental Organization
IPPF	International Planned Parenthood Federation
MARP	Most-At-Risk Population
MSM	Men who have Sex with Men
NGO	Non-Governmental Organization
NSACP	National STD & AIDS Control Programme
OI	Opportunistic Infection
PLHIV	Person/people living with HIV
RSA	Rapid Situation Assessment
STI	Sexually Transmitted Infection
UNAIDS	Joint United Nations Programme on HIV & AIDS
UNHCR	United Nations High Commission for Refugees
VCT	Voluntary Counseling and Testing

EXECUTIVE SUMMARY

This People Living with HIV Stigma Index report is a result of a series of consultations with key stakeholders including membership of three networks of HIV positive people, and the National Partnership comprising of UN joint team on AIDS, the National STD & AIDS Control Programme and the Family Planning Association of Sri Lanka. During these consultations we reviewed the findings of the Stigma Index and formulated strategies on how best to use this document as a tool for advocacy, education, and prevention in Sri Lanka. Both the National Partnership and the positive network membership agreed on the need for a focused approach, rather than general dissemination of the results.

For example, results around access to treatment; including ART, OI medication and reproductive health options and issues of disclosure and confidentiality related to medical settings, should be discussed primarily with the health sector and used to *assist* the health sector and practitioners further develop skills on dealing with HIV positive people in Sri Lanka. This is especially important in a setting where HIV positive people are reluctant to disclose their status to family and friends, and often receive no support or advice outside of their visits to the clinic. Furthermore, given that medical practitioners, especially doctors are largely considered above reproach (god-like) by patients and are the primary source of knowledge and information for HIV positive people in Sri Lanka, the issue of possible stigma and discrimination in healthcare settings need to be addressed.

While the high levels of internalized stigma and corresponding decisions – not get married (>45%), not have sex (>35%), not have children (>75%) **– may have their root in interaction with healthcare professionals**, the results on internalized stigma – feelings of shame (>50%), self-blame (>50%) and guilt (>40%) – also show a **clear need for positive networks in Sri Lanka to introduce and/or strengthen positive living components**. Positive living components, even as we assist the health sector to revisit their practices, can help a Positive Network membership gain the knowledge and skills to live full and productive lives. The results on internalized stigma or how HIV positive people view themselves is also a clear indication of how much more requires to be done by all stakeholders in Sri Lanka to *normalize* living with HIV.

The Stigma Index also clearly points to a complete lack of knowledge and understanding of rights. Sri Lanka currently has no policy or law pertaining specifically to the rights of HIV positive people, however even the knowledge of basic human rights is poor, as is knowledge of available provisions under existing laws and policies. The Stigma Index can be used as a tool therefore to inform law and policy makers, encourage legal professionals to become potential advocates for rights of HIV positive people, and educate HIV positive people on their rights and available legal options.

The demographic data gathered though the Stigma Index suggests that HIV positive people largely belonged to **low socio-economic strata** (annual *household* income levels below USD 3000 for 74%, with only 1% earning more than USD 5000) with low levels if education (almost 60% only achieved a maximum of primary education and >30% received secondary education) and a **largely provincial or rural locus** (80% approx). This information is validated by the Positive Networks, from whose membership the respondents were randomly selected. This also helps us understand the perception of infallibility with regard to healthcare professionals. Anecdotal evidence indicates that HIV positive people from middle class, affluent backgrounds do exist but largely ignore the positive network membership and also do not depend on the Sri Lankan health sector for treatment.

In a nutshell, the respondents to the Stigma Index have **poor knowledge of rights**; they are **reluctant to disclose their status** to family and friends and therefore **lack crucial social support**; and they are totally **dependent on the government health sector for treatment**.

This report makes specific recommendations to address the needs of people living with HIV in Sri Lanka, as identified through the Stigma Index, focusing primarily on Health Care Settings, Law and Rights and Positive Living. This report recognizes that while external conditions of stigma and discrimination need to be addressed, HIV positive people in Sri Lanka require the capacity and skills to educate each other on life after HIV, and how they can live positive and productive lives free from fear, and be conscious of their rights; rights they may have to fight for; a fight that they must believe they can win.

BACKGROUND

HIV and Stigma in Sri Lanka

"Currently Sri Lanka is experiencing a low level HIV epidemic. The estimated number of people living with HIV as at end 2009 was 3000 and the estimated HIV prevalence among adults (15-49 years) is less than 0.1%. Survey data observes that even among individuals considered at higher risk of infection on the basis of their occupation, behaviors and practices, the HIV prevalence is below 1% up to end of 2009. As at end December 2009, a cumulative total of 1196 HIV persons were reported to the NSACP. The main mode of transmission is due to unprotected sex between men and women (82.8%). Men who have sex with men have accounted for 11.2% of the transmission while mother to child transmission was 5.4%. Transmission through blood and blood products was 0.4%. Injecting drug use in Sri Lanka is not a common phenomenon. However, certain socioeconomic and behavioral factors which are present in the country may ignite an epidemic in the future. The presence of a large youth population, internal and external migration, clandestine but flourishing sex industry, low level of condom use, concurrent sexual relationships among most-at-risk-populations (MARP) are some such factors. Low level of sexually transmitted infections (STI), availability and accessibility to free of charge health services from the state sector, high literacy rate, low level of drug injectors, are factors considered to be protective."[1]

The UNGASS Report currently provides the most detailed information available on HIV in Sri Lanka and provides the necessary backdrop for the discussion of HIV related stigma and discrimination in Sri Lanka. The UNGASS Report also refers to the National Strategic Plan (2007-2011) that guides the national response, which includes "mitigating stigma and discrimination to improve the quality of life of people infected with or affected by HIV"[2]

How stigma and discrimination has been mitigated and the increase in the quality of life of HIV positive people is difficult to measure. Information on experiences of stigma and discrimination are largely anecdotal and fragmented. Interaction and discussion with Positive Networks suggests that stigmatizing attitudes and behaviour exist among family, colleagues, friends, healthcare sector, employers, and even religious leaders, but no documented evidence exists. Often information on stigma and discrimination has to be extrapolated from research on HIV Knowledge, Attitudes and Behaviour studies. For example, in a HIV & AIDS Rapid Situation Assessment (RSA) of the Maritime Sector in Sri Lanka, conducted in January 2010, students from across three maritime schools in the country (Colombo, Panadura, Galle) showed that knowledge of HIV transmission and transmission myths does not necessarily reduce stigmatizing attitudes towards people living with HIV. Over 90% of students identified the modes of transmission correctly, and over 80% identified existing myths of transmission correctly (including use of the same toilet facilities, speaking with and touching people living with HIV, and being sneezed on by people living with HIV) but when asked if they would work alongside people living with HIV (49%), share tools and equipment (37%) or share a room (35%) these numbers dropped dramatically.[3]

The strength of the Stigma Index is that distinctive voices of HIV positive people in Sri Lanka will be heard for the first time discussing *their* perceptions and experiences of stigma and discrimination, and what it means to them to be HIV positive. This is neither an anecdotal fragmented account nor is it dependent on extrapolations from HIV related behavioural research with non-HIV positive target groups. And with 2011 approaching the Stigma Index conducted two years into the strategic plan is a good indicator to measure the successes and challenges of the National Strategic Plan (2007-2011).

What is the People Living with HIV Stigma Index?

The People Living with HIV Stigma Index is a joint initiative that has been developed and implemented by and for people living with HIV. Those involved in design and development of this survey tool (since 2005) include the Global Network of People Living with HIV/AIDS (GNP+); the International Community of Women Living with HIV/AIDS (ICW); the International Planned parenthood Federation (IPPF); and the Joint United Nations Programme on HIV/AIDS (UNAIDS).

The Stigma Index aims to a) Document various experiences of people living with HIV within a particular community or country regarding HIV related stigma and discrimination; b) Compare situations of people living with HIV in one country or across different countries with respect to a particular issue; c) Measure changes over a period of time to ascertain if conditions for people living with HIV have improved or worsened with regard to stigma and discrimination; d) Provide an evidence base for policy change and

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[1] UNGASS Country Progress Report Sri Lanka 2010, p.4

[2] Ibid, p.15

[3] HIV & AIDS Rapid Situation Assessment Maritime Workers 2010

programmatic interventions; and e) Use the Stigma Index as a local, national and global advocacy tool to fight for improved rights for people living with HIV.[4]

The Stigma Index tool is designed to gather detailed information on:

- Personal information - relationship status, education, employment and household income levels
- Experience of stigma and discrimination from others
- Access to work, health and education services
- Internal Stigma
- Knowledge of rights, laws and policies
- Experiences of effecting change - including efforts to challenge, confront or educate someone with stigmatizing behaviour
- Experiences around testing and diagnosis; h) Issues of disclosure and confidentiality
- Knowledge and experiences around treatment
- Knowledge and experiences around having children
- General problems and challenges

"The process of implementing the index is intended to be an empowering one for people living with HIV, their networks, and local communities."[5] This is the most significant feature of the Stigma Index; the full and complete participation of people living with HIV in the (design and) implementation of the Stigma Index. The User Guide clearly states: The People Living with HIV Stigma Index is not intended to be an abstract academic exercise that is done 'to' our community… People living with HIV will be at the centre of the process as interviewers and interviewees and as drivers of how the information is collected, analysed and used."[6] It was designed to be a part of a process of empowerment for the interviewees and the interviewer in discussing the experiences of stigma and discrimination faced by them. The Sri Lanka research team reported how emotional and empowering certain interviews were, with both interviewee and interviewer breaking down over particularly difficult accounts of stigma. The empowerment came through the feeling that they were not alone, and that they had been given an opportunity to speak of what had happened to them.

The People Living with HIV Stigma Index also recommended the establishing of a National Partnership that will be responsible for implementing the index. The National Partnership in Sri Lanka includes UNAIDS, FPA Sri Lanka (representing IPPF), Lanka+ and Positive Hopes Alliance who represent GNP+ and ICW. The National STD & AIDS Control Programme (NSACP) have also been involved with the implementation process and have thus far provided technical assistance during the translation process of the Stigma Index questionnaire.

More information on the People Living with HIV Stigma Index, including the latest news, results and challenges faced during global implementation is available on www.stigmaindex.org.

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[4] People Living with HIV Stigma Index – User Guide 2008, p.4

[5] Ibid, p.9

[6] Ibid

METHODOLOGY

Following the 2008 regional consultation in Katmandu, the People Living with HIV Stigma Index methodology was introduced to South East Asia. Three representatives from Sri Lankan networks of people living with HIV attended this consultation and following their return, a National Partnership was formed to coordinate implementationwhich included NSACP, UNAIDS, FPA, and representatives of the networks. The National Research Consultant was then recruited for implementation under the guidance of the National Partnership.

The Sri Lanka People Living with HIV Stigma Index was implemented in three phases. Phase I (June – September 2009) included selection and training of the Stigma Index research team, and completion of 60% of the interviews. Phase II (November 2009 – March 2010) included completion of the remaining 40% of interviews, data entry, analysis and reporting. Phase III (April to June 2010) included consultation with principle stakeholders on key findings and strategies moving forward in-country.

The People Living with HIV Stigma Index has **clear guidelines** as to the processes and procedures of the index. It was requested that the **questionnaire should not be changed or adapted in any way**. This was adhered to in Sri Lanka, and while there was provision to add sections, the research team after consultation with people living with HIV decided it was adequate for Sri Lankan contexts, and pains were taken to accurately translate it into both Sinhalese and Tamil. **All interviewers were people living with HIV**[7]; the Sri Lankan interviewer team consisted of seven people living with HIV, Four women and three men. This included two native Tamil speakers (one man and one woman). **Interviewers were drawn from existing networks**[8] which included **Lanka+** (5 members) and **Positive Hopes Alliance** (2 members). We conducted a **three-day training programme** for interviewers at FPA Colombo to provide participants with an understanding of the history, rationale and the partners involved in the People Living with HIV Stigma Index; an opportunity to consolidate their own understanding of the key concepts associated with HIV related stigma and discrimination, and to reflect on some of their own experiences of these; a thorough understanding of the content of the questionnaire, and the associated forms and agreements that are administered as part of the interview process; the skills to conduct and record interviews with people living with HIV in their community using appropriate methods; and guidance as to how one would reflect on the data that have been gathered during the interview process and be able to access the necessary support from the team leader.[9] The translated questionnaire was further refined during this training programme along with the key related concepts.

Respondents were **randomly selected** from the network memberships, and also included those non-members who were in contact with the networks. Phase I included respondents from urban, provincial and rural communities with interviewers traveling as north as Anuradhapura, as south as Matara, and as east as Batticoloa. Phase II focused mainly on respondents from the Colombo and Kandy districts.

Stigma Index guidelines ensured that interviewees were clear on the nature and scope of the interview, and provided **verbal or written consent** before commencement.[10] Interviewers also ensured that they worked together with the interviewee (side-by-side-interviewing) to complete the questionnaire.[11] Completed questionnaires were returned to the Team Leader for quality review. This was followed by a debriefing to discuss interviewer experiences during implementation. This proved significant in gathering qualitative data on the overall Stigma Index process.

Data entry and analysis was carried out using the recommended program **Epi-Info** developed by the Centre for Disease Control and Prevention (CDC). Questionnaires are currently archived as per **unique identifying codes** and stored under lock and key by the Team Leader. Post data analysis a draft report was prepared, discussed with the research team and then shared with the National Partnership. Presentations on key findings in both English and Sinhalese were used for the respective consultations with the National Partnership and positive network membership to discuss and plan future strategies using the Stigma Index as an advocacy tool.

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[7] "Being interviewed by another person living with HIV does make a difference as you feel they really would understand more about how you feel about things related to being HIV positive." – Researcher, Pilot Workshop, South Africa, Ibid

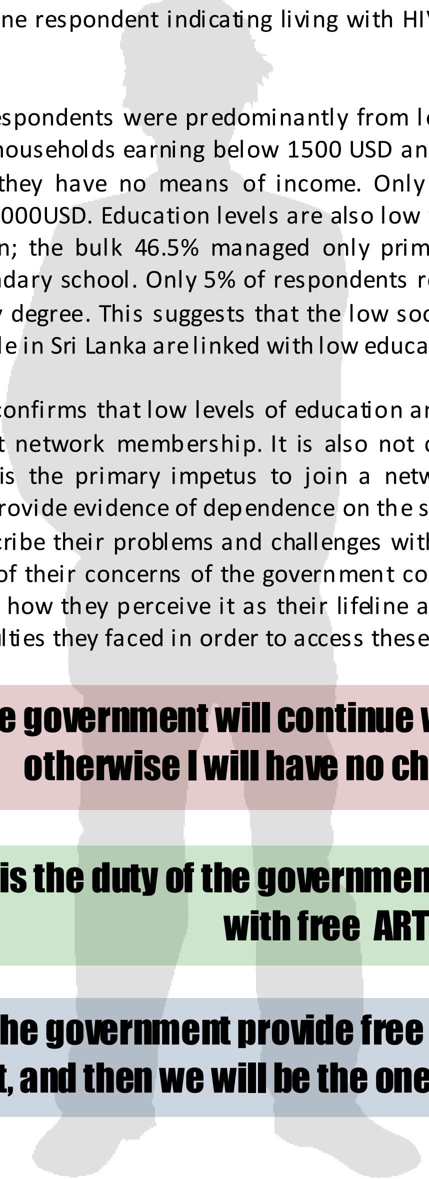
[8] "The process of implementing the index is intended to be an empowering one for people living with HIV, their networks, and local communities." Ibid, inside front cover

[9] Ibid, p. 59

[10] "Get informed consent before the interview starts and make certain that the interviewee would genuinely like to be part of the process and is not just saying 'yes' because s/he feels pressurised to do so." – Researcher, Pilot Workshop, South Africa, Ibid, p.11

[11] "Try to reduce the power imbalance between yourself and the interviewee by sitting alongside the interviewee, and sharing information about some of the more difficult concepts with the interviewee" – Researcher, Pilot Workshop, South Africa, Ibid, p.9

Who is HIV positive in Sri Lanka?



The majority of the Stigma Index respondents were over the age of 35 with near equal distribution of sexes. They have been living with HIV for various periods, with only one respondent indicating living with HIV for more than 15 years.

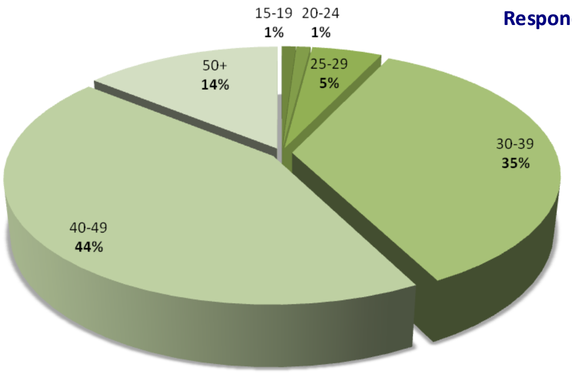
The Stigma Index respondents were predominantly from low socio-economic strata with 63% of households earning below 1500 USD annually and another 8% indicating that they have no means of income. Only 1% of households earned more than 5000USD. Education levels are also low with 14% receiving no formal education; the bulk 46.5% managed only primary education and 34% attended secondary school. Only 5% of respondents received a technical college or university degree. This suggests that the low socio-economic levels of HIV positive people in Sri Lanka are linked with low education levels.

The research team confirms that low levels of education and economic status is common amongst network membership. It is also not clear if material or emotional support is the primary impetus to join a network, however the Stigma Index does provide evidence of dependence on the state for treatment. When asked to describe their problems and challenges with ART, over 70% of respondents spoke of their concerns of the government continuing with FREE ART, they discussed how they perceive it as their lifeline and, some spoke of the economic difficulties they faced in order to access these free services.

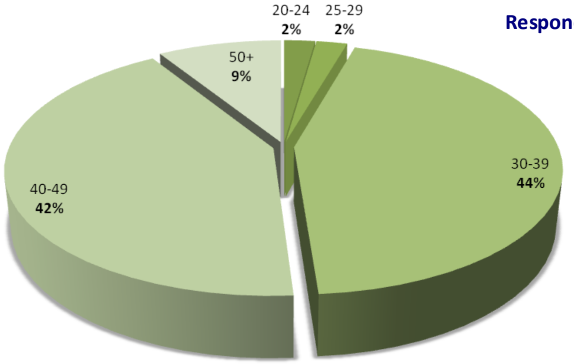
> **“I hope the government will continue with free ART, otherwise I will have no chance to live.”**

> **“It is the duty of the government to continue with free ART for all of us.”**

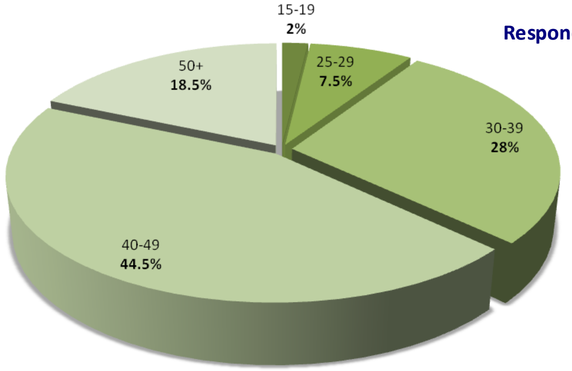
> **“Will the government provide free ART forever? I doubt, and then we will be the ones in trouble.”**



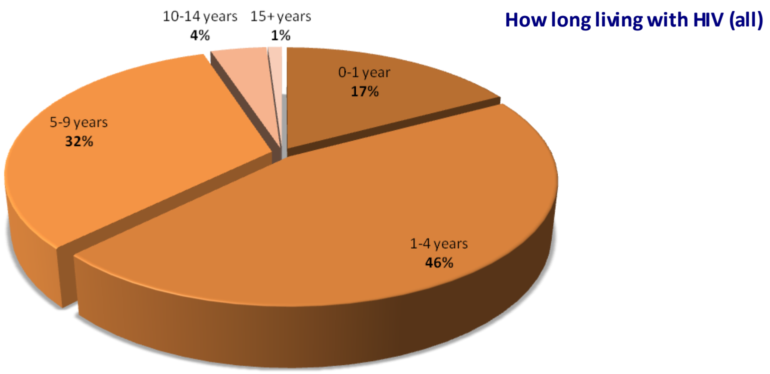
Respondent age (all)



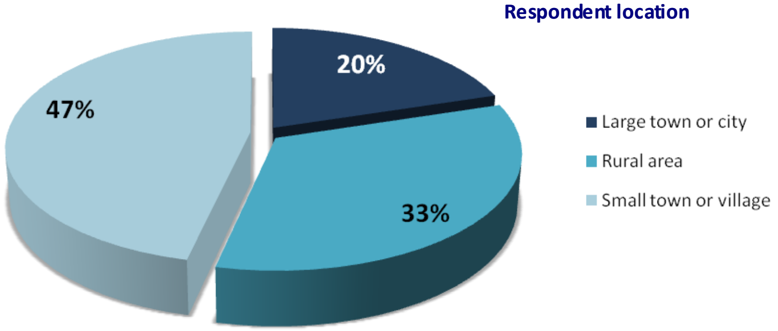
Respondent age (women)



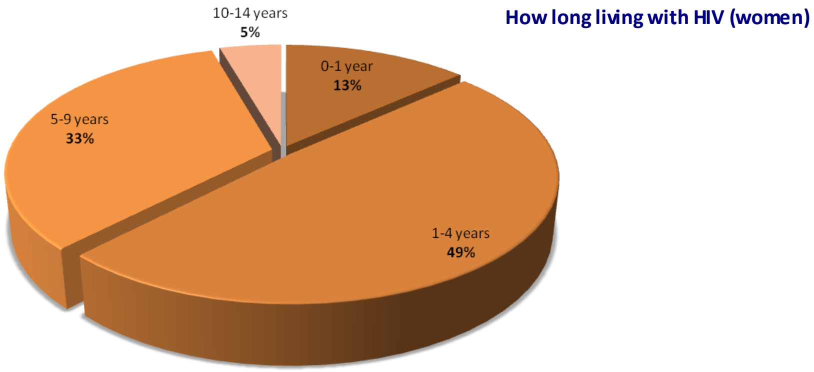
Respondent age (men)



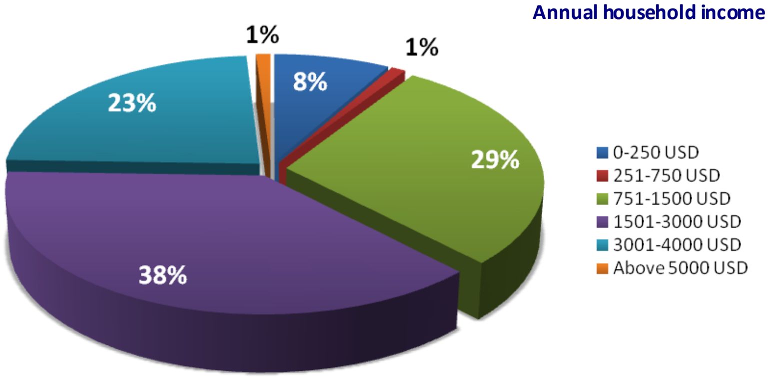
How long living with HIV (all)



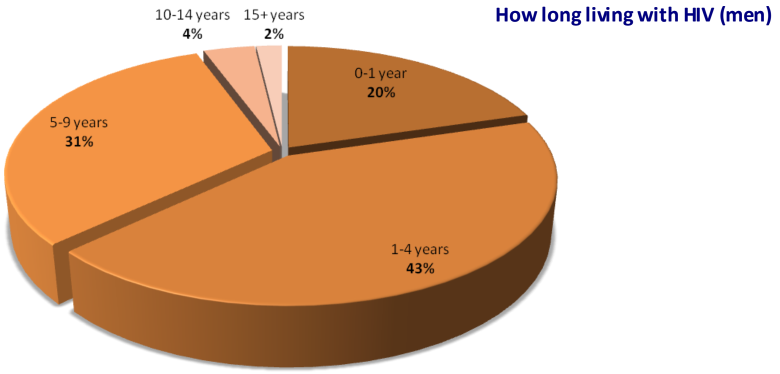
Respondent location



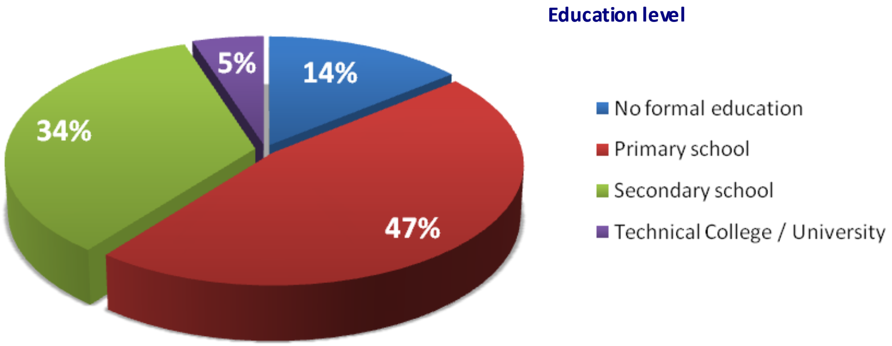
How long living with HIV (women)



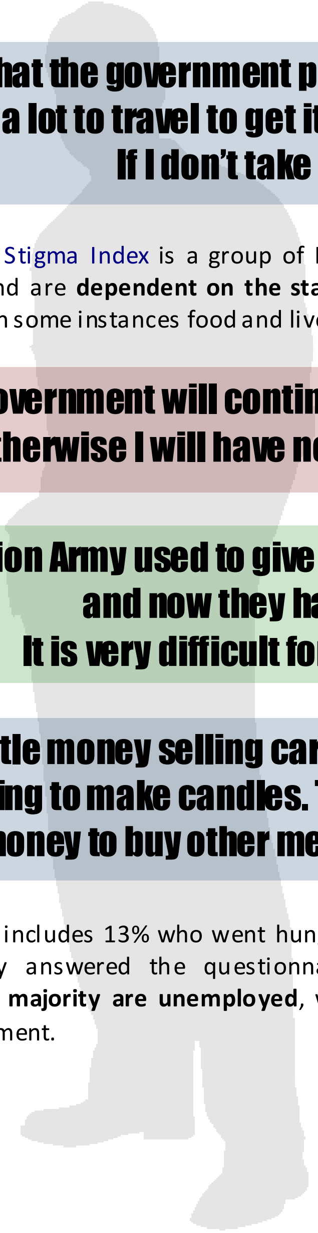
Annual household income



How long living with HIV (men)



Education level



> **"Thank God that the government provides free ART, but it costs me a lot to travel to get it. But what to do? If I don't take it then I will die."**

What emerges from the Stigma Index is a group of HIV positive people that **struggle economically** and are **dependent on the state and other actors** for treatment, support and in some instances food and livelihood support.

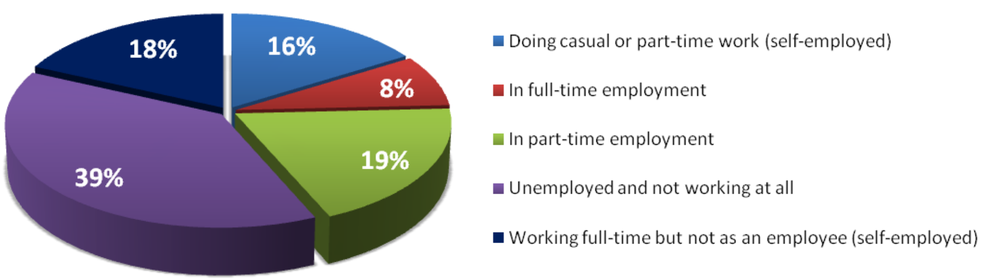
> **"I hope the government will continue with free ART, otherwise I will have no chance to live."**

> **"The Salvation Army used to give us food packets, and now they have stopped that. It is very difficult for us to find food."**

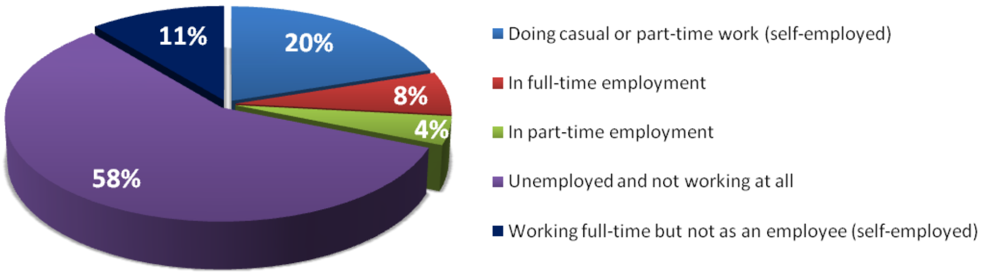
> **"I make a little money selling cards, and now I am learning to make candles. This will help me find money to buy other medication I need."**

Evidence of dependence includes 13% who went hungry for up to 10 days in the month before they answered the questionnaire and their current employment status**. The majority are unemployed**, with only 8% who have retained fulltime employment.

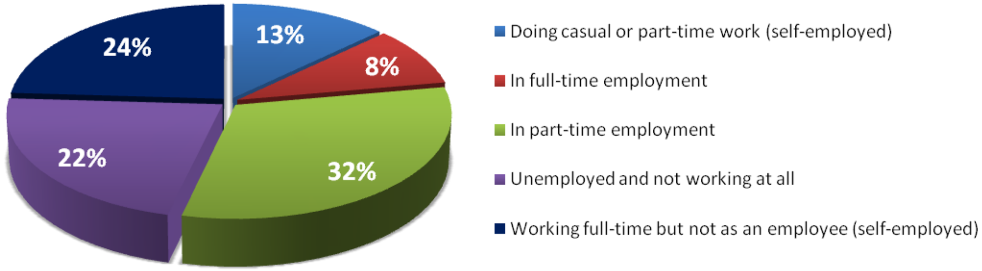
Current employment status (all)



Current employment status (women)



Current employment status (men)



Only 8% of respondents are in full-time employment

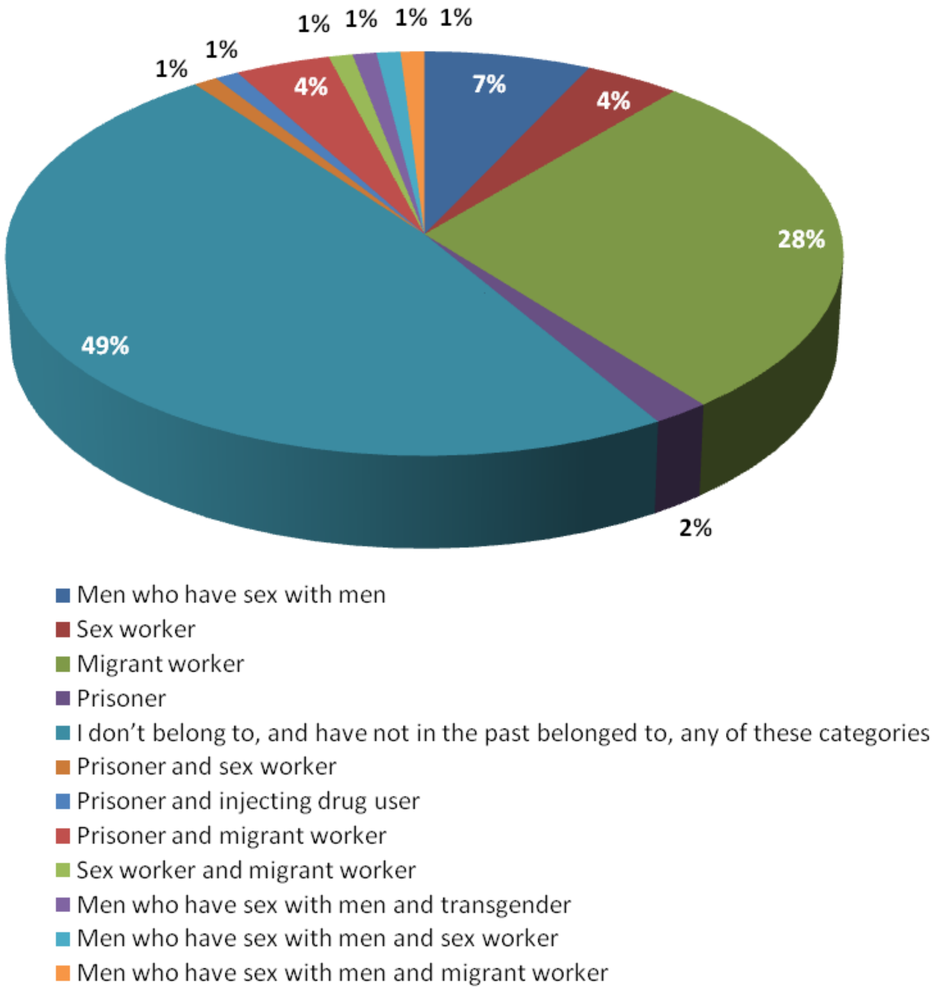
Loss of employment has little association with HIV status (and this is **indicative of the secrecy and general non-disclosure of HIV status**) and therefore poor levels of education, socio-economic status and also a largely provincial/rural locus may have roles to play in contributing to HIV status.

There emerges a stereotypical profile of HIV positive people in Sri Lanka. They are poor. They are uneducated. They are ignorant of the ways of the world.

Vulnerable key populations that are HIV positive include migrant workers (33%) with near equal distribution between men and women. The UNDP report 'HIV Vulnerabilities of Migrant Women: from Asia to the Arab States' states that "various reports assert that of all women living with HIV in Sri Lanka, 20 – 48 percent are returning migrants."[12] This report also discusses that none of the 15 HIV positive participants in the Sri Lankan study "had heard of the virus prior to contracting it, and nearly half were uncertain about how they could spread it."[13] During the dissemination of key findings to approximately 30 HIV positive people from three networks in Sri Lanka, every single member spoke of a link to migrant work. They were either migrant workers themselves, or had a spouse or partner who was a migrant worker.

The other vulnerable or key populations that emerged from the Stigma Index were men who have sex with men (10%); prisoners (8%); sex workers (6%) and injecting drug users (1%). This list is indicative of the negative HIV stereotype, also called most at risk populations from HIV. The public health perspective would argue that their increased risk is not due only to their potential to engage in risky behaviour but due to the stigma and discrimination that prevents them from accessing information and services that can help reduce the proclivity for risky behaviour.

Do you belong to, or have you in the past belonged to, any of the following categories?



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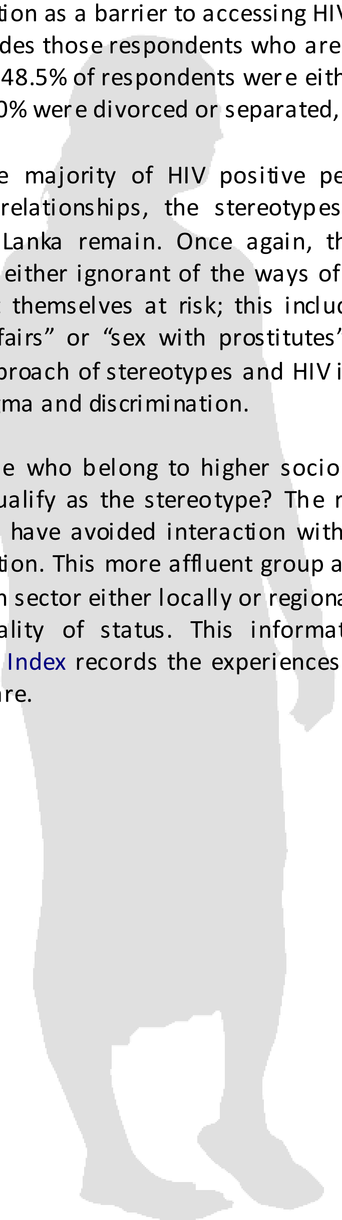
[12] HIV Vulnerabilities of Migrant Women: from Asia to the Arab States, p.85

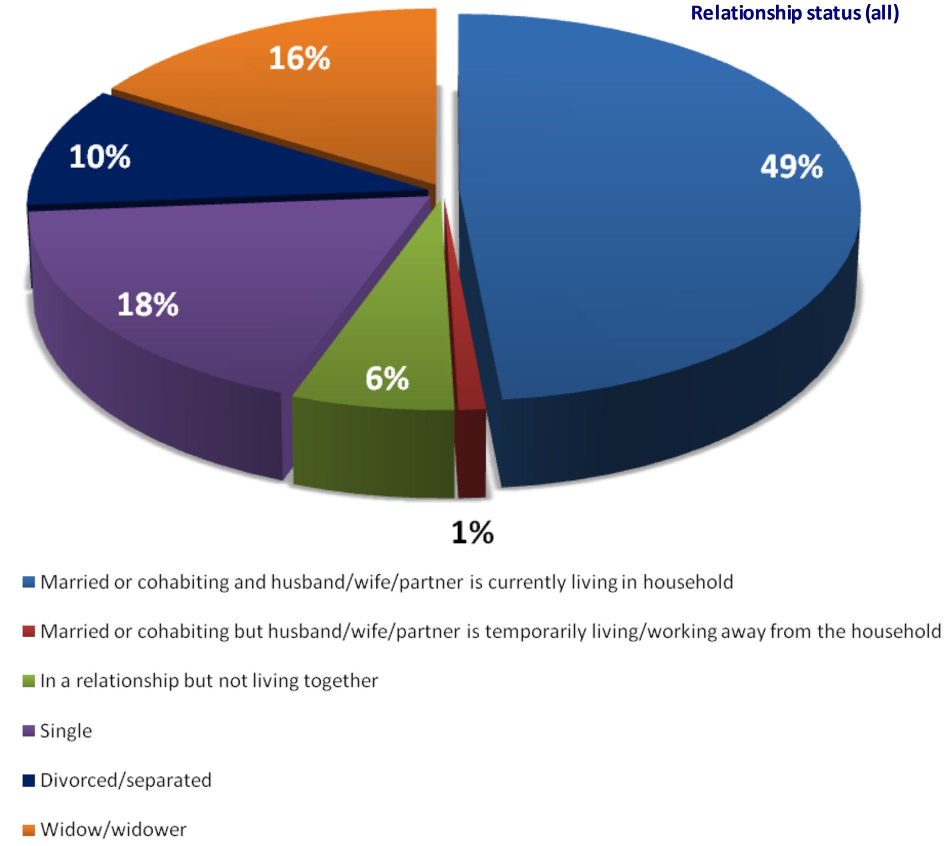
[13] Ibid, p.86

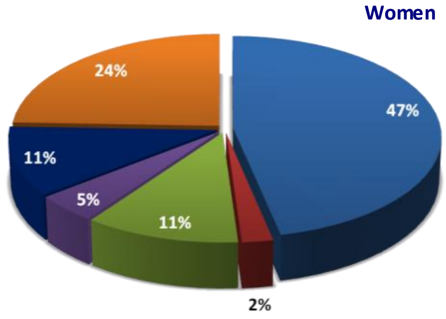


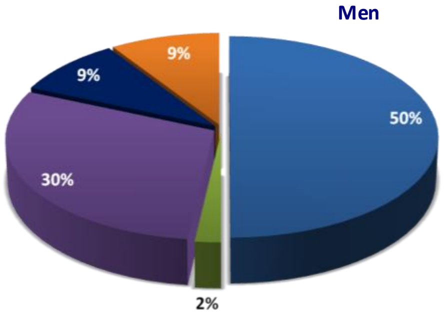
Stigma and discrimination as a barrier to accessing HIV prevention information and services also includes those respondents who are married or have been in married relationships. 48.5% of respondents were either married or cohabiting with their partner.[14] 10% were divorced or separated, and 16% were widowed.

Still, even though the majority of HIV positive people have been within culturally normative relationships, the stereotypes that face stigma and discrimination in Sri Lanka remain. Once again, they are poor. They are uneducated. They are either ignorant of the ways of the world, or belong to communities that put themselves at risk; this includes married people that have "extramarital affairs" or "sex with prostitutes". The Stigma Index will show that it is this approach of stereotypes and HIV in Sri Lanka that lends to the experiences of stigma and discrimination.

Do HIV positive people who belong to higher socio-economic groups exist? People who do not qualify as the stereotype? The research team speaks of how these individuals have avoided interaction with the networks, and also accessing free medication. This more affluent group accesses their medication from the private health sector either locally or regionally (India and Singapore) to ensure confidentiality of status. This information however is purely anecdotal. The Stigma Index records the experiences of only those who have had the courage to share.







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[14] Given Sri Lanka's cultural norms and mores, this statistic is more suggestive of individuals who are married rather than those cohabiting with unmarried partners. Only one instance of non-married partners cohabiting was reported during debriefing sessions.

Experiences of Stigma & Discrimination

This section is broken down into discussions around *general experiences* of stigma (including stigma in the workplace and educational settings) and stigma in *healthcare settings*. To set the context for discussing HIV positive people's experience of stigma and discrimination in Sri Lanka, we have to first discuss their patterns on disclosure.

Descriptions of how (and if) family and community learnt of respondents' HIV status.	I told them	Someone else told them, WITH my consent	Someone else told them, WITHOUT my consent	They don't know my HIV status	Not applicable
	%	%	%	%	%
Your husband/wife/partner	39.4	12.1	4	9.1	40.4
Other adult family members	30.3	9.1	14.1	43.4	7.1
Children in your family	14.1	3	4	54.5	25.3
Your friends / neighbours	1	1	15.2	72.7	12.1
Other people living with HIV	75.8	8.1	5.1	10.1	6.1
People who you work with	2	0	5.1	57.6	36.4
Your employer(s)	0	0	2	37.4	62.6
Your clients	0	0	1	36.4	63.6
Injecting drug partners	0	0	0	1	99
Religious leaders	5.1	01	3	39.4	51.5
Community leaders	3	2	3	34.3	57.6
Health care workers	56.6	11.1	18.2	5.1	13.1
Social workers	8.1	7.1	4	26.3	54.5
Teachers	0	0	3	31.1	65.7
Government officials	4	0	7.1	29.3	59.6
The media	1	0	5.1	28.3	65.7

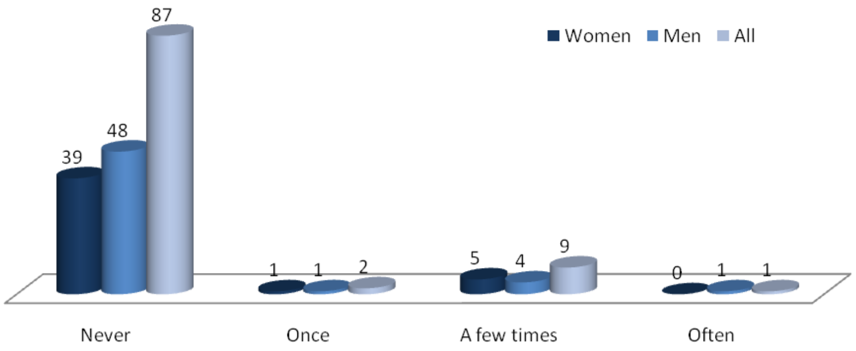
HIV positive people have found it easiest to share their status with other people living with HIV. This is indicative of the majority of respondents belonging to networks in Sri Lanka. In terms of experiencing stigma and discrimination however, it is clear that respondents were not comfortable with friends, neighbours, co-workers, employers, and children finding out their status. In fact even spouses and other adult family members have not been the priority when disclosing HIV status. The research team reported that respondents requested interviews not at their homes or even the general vicinity, but at public places including bus stands, parks, tea shops, often after dark, to ensure that their families remained unaware of what was taking place. It is not clear whether disclosure has been difficult due to stigma and discrimination experienced directly or vicariously through anecdotal accounts of other HIV positive people. What is clear is that these patterns of non-disclosure are the primary reason for recording low levels of experienced stigma through the Stigma Index.

General Experiences

As indicated above due to non-disclosure of HIV status recorded levels of stigma and discrimination remain low. For example, exclusion from social and religious gatherings, and family activities due to HIV status was as low as 10%, 3%, and 5% respectively. And only 5% were forced to change their place of residence due to HIV status.

In the last 12 months, how often have you been excluded from social gatherings or activities?

(Total number people who been excluded = 12)



> **"If people in the village learn of my status**
> **I won't be able to walk on the road.**
> **Only my children know in the village."**

Harassment & Assault

Notably, 12% felt they were verbally harassed and threatened in circumstances specifically related to their HIV status. And 5% were physically assaulted based on their HIV status. **Domestic abuse is under-reported in Sri Lanka**[15], and Sri Lankan culture shares the region’s traditional apathy towards domestic abuse and intimate partner violence. Four women and a man who live with HIV being assaulted by husbands or family members would not be deemed unusual. In fact, the research team through discussion suggests that people would attempt to justify it based on punitive grounds, especially if the individual is perceived to bring shame on the family due to their HIV status.

12% of respondents

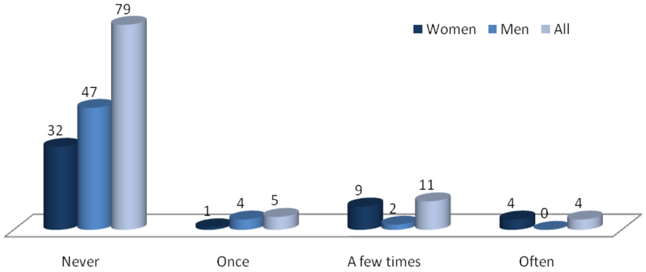
reported **verbal harassment** related to their HIV status

5% of respondents

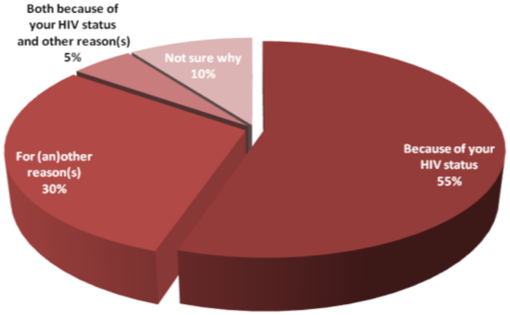
reported **physical assault** related to their HIV status

In the last 12 months, how often have you been *verbally* insulted, harassed and/or threatened?

(Total number people who had some form of verbal harassment = 20)

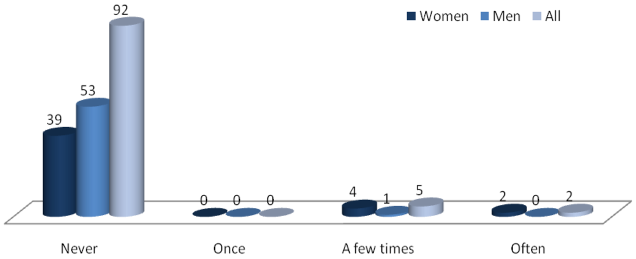


If so, was this…?

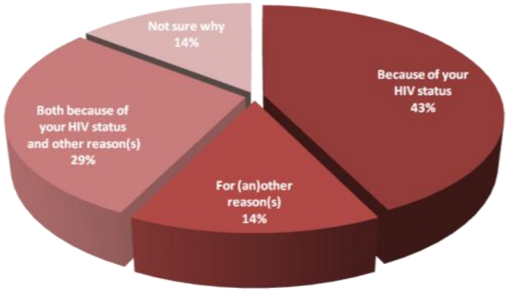


In the last 12 months, how often have you been *physically* harassed and/or threatened?

(Total number people who had some form of physical harassment = 7)



If so, was this…?



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[15] “Most acts and consequences of violence remain hidden and unreported” - Dr. Lakshman Senanayke, co-author, National Report on Violence and Heath in Sri Lanka. http://www.sundayobserver.lk/2008/04/20/imp01.asp

Employment & Education

Of the 11% that indicated they lost their job, the most significant reason that emerged was poor health. Only 4% of respondents indicate they were refused a work opportunity due to their HIV status.

No respondents reported being dismissed, suspended or prevented from attending educational institutions. This could be more reflective of the ages and educational levels of the respondents than it is of the lack of stigma and discrimination towards people living with HIV by educational institutions. Nevertheless, 3% of respondents indicated that due to their HIV status, their children had been dismissed, suspended or prevented from attending educational institutions.

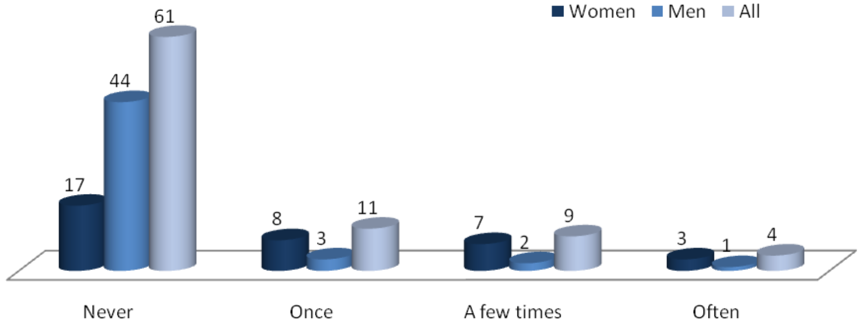
> **Low levels of stigma and discrimination in the Stigma Index are due to non-disclosure of HIV status**

The bottom line remains: **the reported low levels of stigma and discrimination in the Stigma Index are due to non-disclosure of HIV status**.

However, if HIV positive people are reluctant or afraid to disclose their status, this is still an indicator of the high levels of stigma and discrimination they perceive or anticipate. To measure this perceived or anticipated stigma and discrimination by HIV positive people is difficult, yet the Stigma Index does include a section that asks respondents who have experienced stigma and discrimination on *why* they think people stigmatized or discriminated against them. Their answers indicate the need for a less deterrent approach to HIV prevention programming in Sri Lanka to which a pre-HAART 1980s, early 1990s 'AIDS is a Death Sentence' scare strategy is still central. **It is a strategy that failed**. It is a strategy that has proved to be an obstacle to HIV prevention, and a definite obstacle to HIV positive people accessing services.

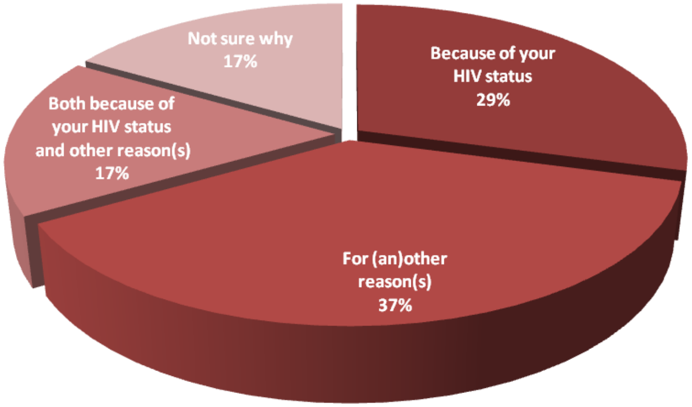
In the last 12 months, how often have you lost your job (if employed) or another source of income (if self-employed or an informal/casual worker)?

(Total number people who had some form of income = 85)



If so, was this…?

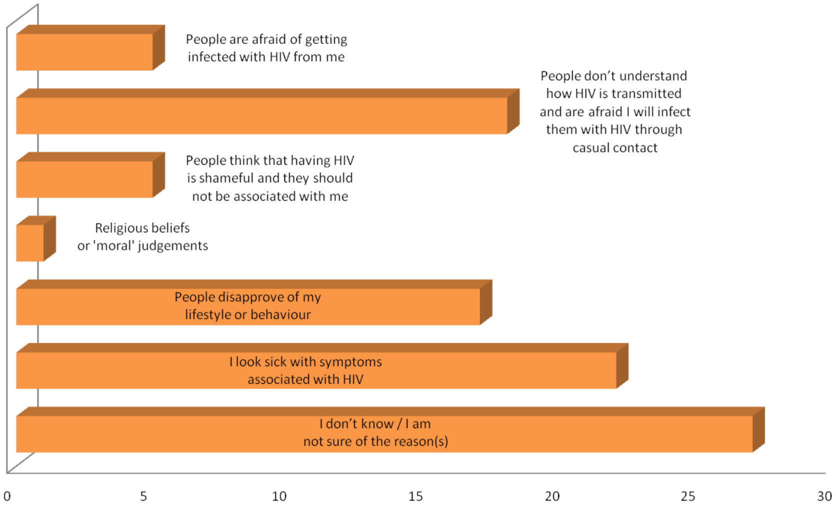
(Total number of people who lost their jobs or income = 24)



People are afraid of us. This fear is based on ignorance. People do not have accurate and comprehensive knowledge of HIV transmission. People are ashamed to be associated with me. I look sick. This insight into public perception is accurate and supported by personal accounts of research team members who have endured stigma and discrimination (related to casual transmission) even from non-HIV positive co-workers and colleagues working with them on HIV prevention education and support programmes.

These results are also indicative of how HIV positive people view themselves. “I look sick” is readily translated from “I am sick”, which in turn comes from the diagnosis “you are sick.” In a time when bug chasing[16] – aberrant to most – remains a practice in environments where HIV is chronic and manageable, in a time when HIV, even in the developing world, if identified and treated, is a chronic and manageable condition, this focus on sickness needs revisiting. If the Stigma Index points to anything, it points to the need for positive living – how to live positive, productive and full lives with HIV – in Sri Lanka. Positive living that requires assistance and support from healthcare workers.

If you have experienced some form of HIV-related sigma and/or discrimination in the last 12 months, why do you think this is?



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[16] http://en.wikipedia.org/wiki/Bugchasing

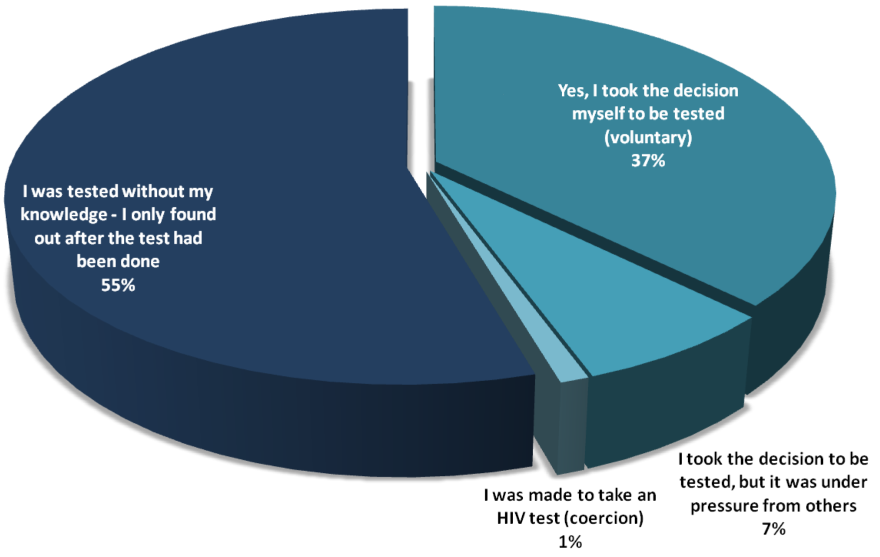
Stigma in Healthcare Settings

This section is divided into 3 key areas: Testing & Diagnosis; Confidentiality & Disclosure; and Care & Support (including Reproductive Options).

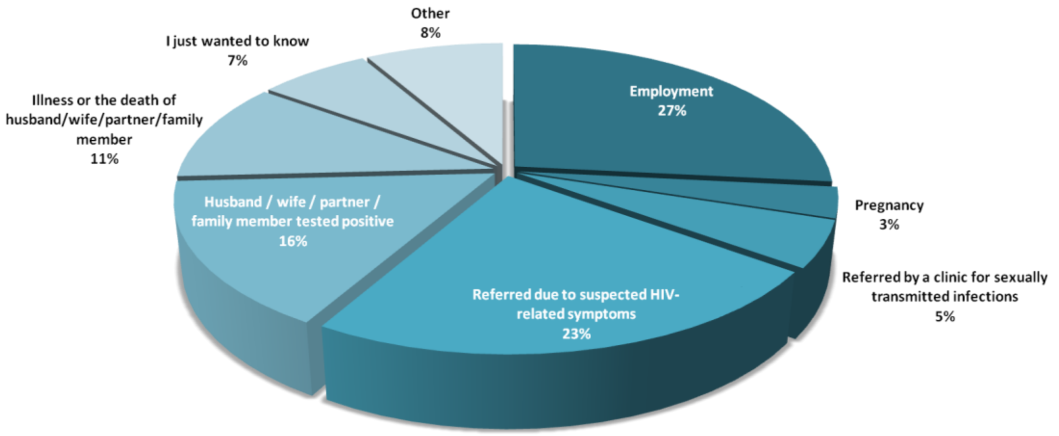
Testing & Diagnosis

The majority of Stigma Index respondents were tested without their knowledge. This includes **78% of those tested for employment**, which emerged as the most common reason for testing. The report on HIV Vulnerabilities of Migrant Women gives us further insight: “Blood and urine tests (for HIV and pregnancy, respectively) are mandatory for legally migrating women prior to their departure. The test results are provided directly to the agents, and many of the interviewed women admitted to being in the dark about the nature of these tests.”[17]

Was the decision to get tested for HIV up to you?



Why were you tested for HIV?



The UNDP report on Migrant Workers together with 79% of Stigma Index respondents who reported that they received only post test counseling, indicates poor implementation of NSACP guiding principles. Section 3.2 of the National Strategic Plan 2007-2011 *Respect for Human Rights* clearly states: “HIV testing without prior informed consent is never acceptable (unless anonymous unlinked for screening purposes) and each HIV test result has to be confidential.”

> **“HIV testing without prior informed consent is never acceptable (unless anonymous unlinked for screening purposes) and each HIV test result has to be confidentiaL”**
>
> **Section 3.2 of the National Strategic Plan 2007-2011 Respect for Human Rights**

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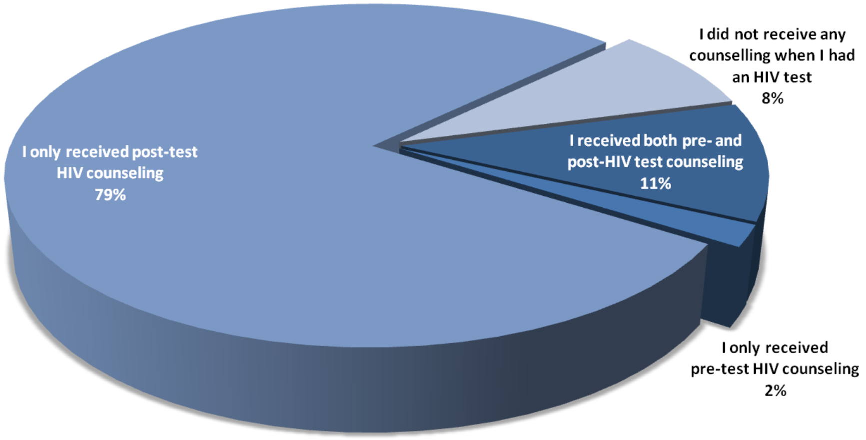
[17] HIV Vulnerabilities of Migrant Women: from Asia to the Arab States, p.86

Did you receive counseling when you were tested for HIV?



8% of Stigma Index respondents received no counseling either before or after testing positive. These are people who had to cope with their result based on their limited understanding of HIV, which they **equated with a death sentence**, given the prevalent strategies of prevention in Sri Lanka. They had to wait until their appointment with a healthcare professional for treatment to learn of life options after HIV.

Pre-test counseling prepares an individual for the HIV test. It allows for discussion of fears and doubts related to the test, and also mitigates the fear of receiving a death sentence. If correctly administered with discussions on lifestyle changes (regardless of the result) it can be an effective prevention tool and an opportunity for the test candidate to receive accurate and comprehensive information on living with HIV. Pre and post test counseling are the first steps in the continuum of care for a person living with HIV. **Ignoring these first steps are a violation of human rights and a lost opportunity for both prevention and positive living.**

8% of respondents received no counseling whatsoever

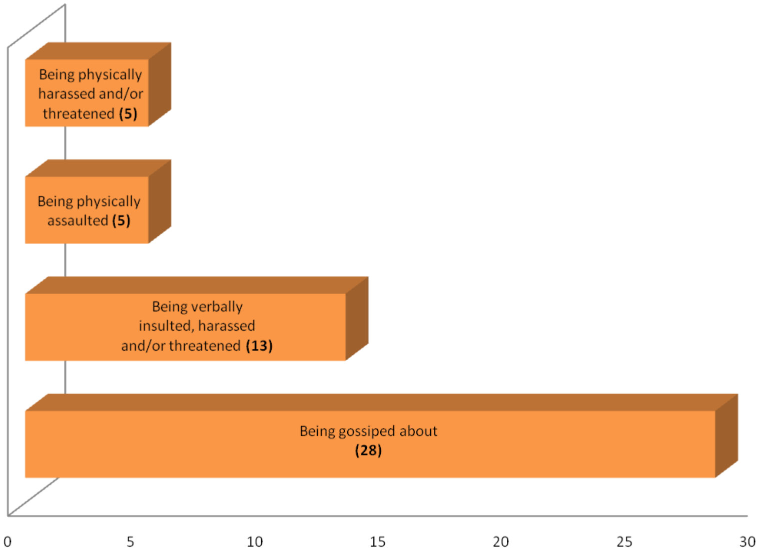
Confidentiality and Disclosure

When Stigma Index respondents were asked to discuss problems and challenges related to HIV testing and diagnosis, their main issues were around confidentiality and disclosure. One respondent recorded:

> **“I am afraid that people will get to know about my status because hospital workers gossip.”**

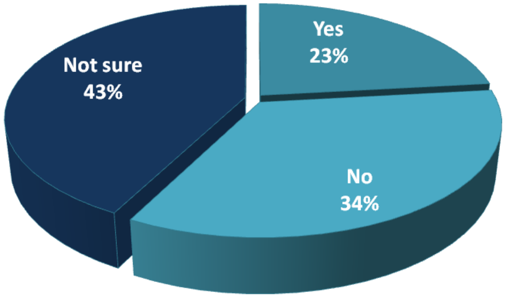
More than 65% of respondents echoed similar feelings through their written comments at the end of the questionnaire. This fear of being gossiped about is the primary fear HIV positive respondents had, and obviously will intensify when associated with healthcare workers who have accurate knowledge of their HIV status.

In the last 12 months, have you been fearful of any of the following things happening to you?



Furthermore, anecdotal evidence was offered by the research team and respondents on how their status was communicated by hospital workers to their village or community resulting in ostracization, physical assault and damage to property. It is no surprise therefore that the Stigma Index results indicate that HIV positive people in Sri Lanka do not absolutely trust that their confidentiality is maintained by healthcare workers with 42% indicating they are not sure whether healthcare workers have disclosed their status, and 23% claiming they have actual knowledge of healthcare workers disclosing their status without consent.

Disclosure of HIV status by Healthcare Worker WITHOUT consent



In addition, 64% are not sure as to how confidential their medical records related to HIV status remain. With both these results the majority of respondents are 'not sure', a response that is indicative of the **need for an improved relationship between healthcare workers and HIV positive people**. If the healthcare sector is willing to listen to the concerns of the Stigma Index respondents and take steps to build trust and confidence, in the event the Stigma Index is conducted again these results of confidentiality and disclosure will improve.

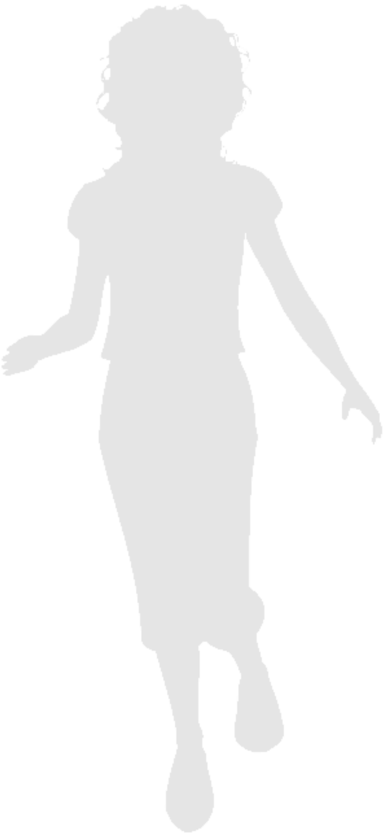
> **"I am doubtful to the extent that my confidentiality is protected. I also don't think disclosure is an option. As soon as you disclose you are persecuted."**

64% of respondents

are not sure that their medical records will be kept confidential

3% of respondents

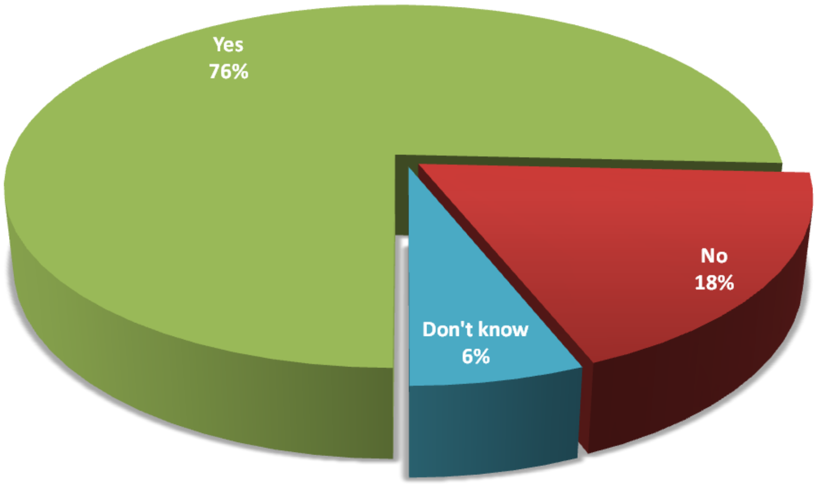
Are certain that their records are definitely not confidential



Care and Support (including reproductive options)

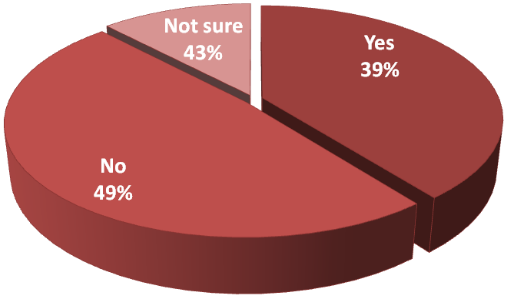
The Stigma Index results show that there is a need for more comprehensive care and support in Sri Lanka. Almost 50% of respondents reported that they have had no discussions with healthcare professionals on HIV related treatment options. This is **despite respondents reporting ready access to antiretroviral therapy**.

Access to antiretroviral therapy (ART)



Access to ART and discussion around ART regimens including adherence counseling is only part of the continuum of care, and treatment includes medication for opportunistic infections. The research team reported that some respondents had verbally indicated that they didn't understand what kind of medication they were taking for opportunistic infections (OI). The pills were described by colour not by name, and in the event they misplace or lose their medication they do not know what to buy at a pharmacy to continue with the course of treatment. Furthermore, the contrast between access to ART and OI medication could also point the economic status of HIV positive people in Sri Lanka outlined above, given that OI medication is not always made available by the state.

Access to Opportunistic Infection (OI) medication



Care and support does not end with ART or treatment of opportunistic infections. Positive living is about living full and productive lives as a HIV positive person. Normalizing living with HIV medically includes discussing the sexual and reproductive options of HIV positive people. 'Healthy, Happy and Hot: A young person's guide to their Rights, Sexuality, and Living with HIV' a 2010 publication by the International Planned Parenthood Federation states: "Sexual and reproductive rights are recognized around the world as human rights. Every person living with HIV is entitled to these rights and they are necessary for the development and well-being of all people and societies in which they live."

To enjoy these rights HIV positive people need the support of the healthcare sector. The Stigma Index results show that this support is still lacking and that healthcare professionals will have to take steps in improving their interaction with HIV positive people around their sexual and reproductive needs. For example, 56% of respondents have not discussed issues of sexual and reproductive health, sexual relationships and emotional well-being with appropriate healthcare professionals.

64% of respondents have however received specific counseling from Healthcare professionals on their reproductive options. The main objective of these counseling sessions appears to focus on dissuading HIV positive people from having children. 44% reported that healthcare professionals have advised them NOT to have child after being diagnosed HIV positive. 9% speak of being coerced into not having children; and 8% reported that obtaining ART was conditionally based on the use of some form of contraception and 4% (women) indicated that they were coerced into terminating their pregnancy.

49% of respondents

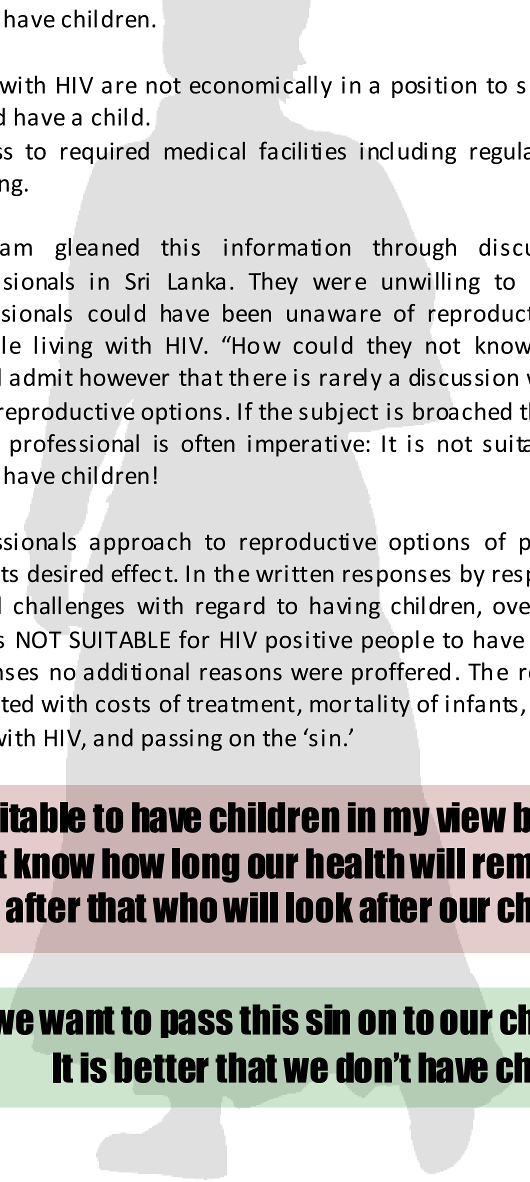
have **not** had a **constructive discussion** with a healthcare professional about

HIV-related treatment options

and only 56%

have had a **constructive discussion** with a healthcare professional about

sexual and reproductive health



These results suggest **violations of HIV positive people's human rights** as outlined above by IPPF. The research team offered the following rationale for the reluctance of healthcare professionals in Sri Lanka to encourage HIV positive people to have children.

1) People living with HIV are not economically in a position to support their treatment and have a child.
2) Limited access to required medical facilities including regular viral load and CD4 testing.

The research team gleaned this information through discussion with healthcare professionals in Sri Lanka. They were unwilling to accept that healthcare professionals could have been unaware of reproductive options available to people living with HIV. "How could they not know? They are doctors." They did admit however that there is rarely a discussion with the HIV positive client on reproductive options. If the subject is broached the response of the healthcare professional is often imperative: It is not suitable for HIV positive people to have children!

Healthcare professionals approach to reproductive options of people living with HIV has had its desired effect. In the written responses by respondents on the problems and challenges with regard to having children, over 77% have indicated that it is NOT SUITABLE for HIV positive people to have children. In 64% of the responses no additional reasons were proffered. The rest spoke of difficulties associated with costs of treatment, mortality of infants, longevity of parents who live with HIV, and passing on the 'sin.'

> **"It is not suitable to have children in my view because we don't know how long our health will remain like this and after that who will look after our children."**

> **"Why do we want to pass this sin on to our children? It is better that we don't have children."**

Only one respondent spoke vaguely of people's rights to have children:

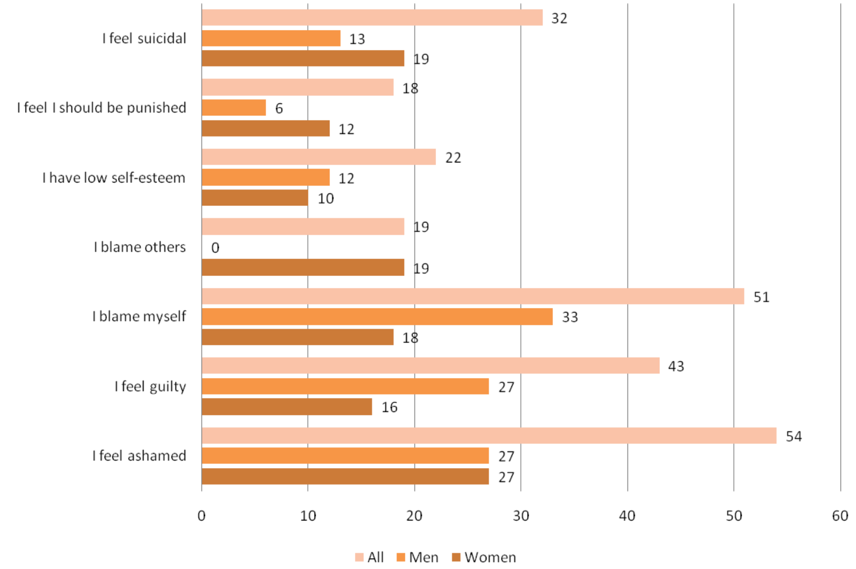
> **"Everyone would like to have a child. It is children that help us live for the future. So there should be advice and medication given to those who want to have children, even if they are HIV positive."**

If healthcare professionals do not support positive living in Sri Lanka, positive living interventions will fail. The positive networks and other civil society organisations that work with HIV positive people need to garner the support of the healthcare sector. Talk of rights and policies and laws is futile if healthcare professionals, who are perceived as the source of knowledge on life after HIV are not in agreement that HIV positive people can clinically live productive and full lives. The next section demonstrates that the decisions that HIV positive people make are based on their experiences of stigma and discrimination, and on information that is available to them on life after HIV.

Stigma Internalised: feelings & decisions of HIV positive people

Internalized stigma appears closely associated with stereotypical behaviour that can result in HIV infection ("extramarital affairs" or "sex with prostitutes"); the fear of disclosure linked to being gossiped about and so excluded by family, friends, and community, not to mention the loss of employment; the information available on living with HIV and the dependence on the government healthcare system.

FEELINGS: In the last 12 months, have you experienced any of the following feelings because of your HIV status?



Stigma Index results show that shame (54%) and guilt (51%) are the most prevalent feelings of both male and female respondents. This is closely followed by self-blame (43%). It is possible, as discussed above that these feelings are exacerbated by the stereotypical behaviours associated with HIV which include unprotected extra-marital sex with female and/or male partner(s); unprotected sex before marriage with female and/or male partner(s); unprotected sex with female and/or male sex worker(s); and injecting drug use. Also media reports, typically around World AIDS Day, where Sri Lanka's low prevalence is often associated with strong cultural values[18] immediately position people already living with HIV outside of these cultural values. This again can lend to feelings of shame, guilt and self-blame, despite being housewives who remained faithful to their husbands and still became HIV positive. The results of 'blaming others' is an indicator of how some women feel they have remained faithful to their partners, with no record of any men blaming anyone but themselves for getting infected.

Furthermore, 32% of respondents who have reported suicidal feelings show that **Sri Lanka cannot afford to ignore people already living with HIV**.

32% of respondents experienced suicidal feelings because of their HIV status

As suggested, **feelings of internal stigma also have a clear impact on life decisions**. These results however also appear to be influenced by information they have received from healthcare professionals, and stigma and discrimination that they have experienced.

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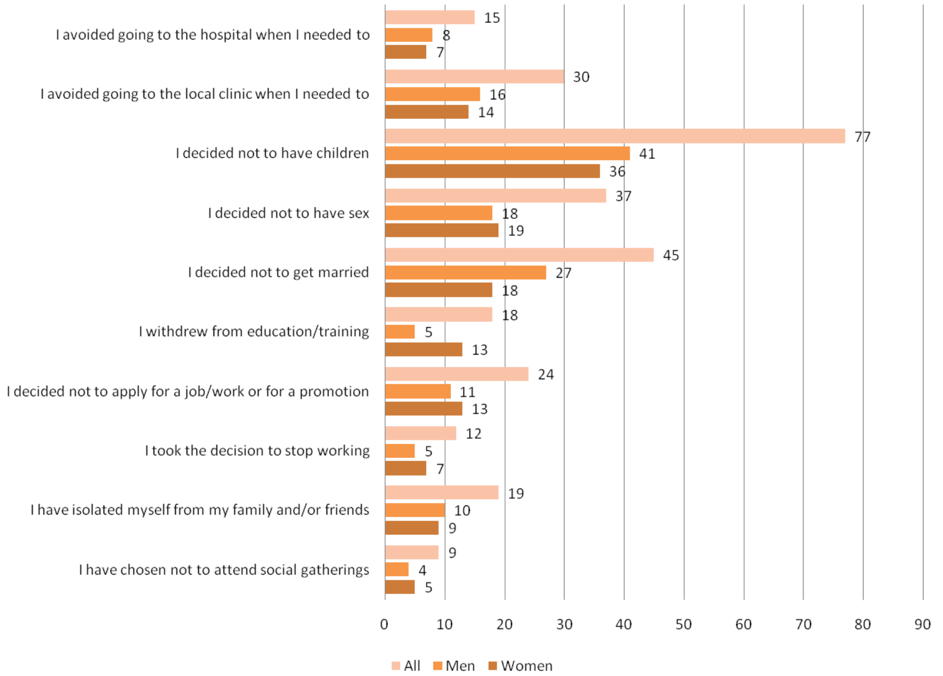
[18] Former Minister of Healthcare and Nutrition, Nimal Siripala de Silva's rationale for Sri Lanka's low HIV prevalence rate: high literacy rate and strong cultural roots. http://www.dailynews.lk/2009/12/01/news23.asp

Decisions around sexual and reproductive health are the most pronounced with 77% deciding against having children; 45% not intending to get married; and 37% deciding not to have sex again. While there could be multiple drivers as outlined for these decisions around sexual and reproductive health, the decision not to attend clinics or hospitals even when in need points to experiences of stigma and discrimination within healthcare settings.

The findings of feelings and decisions in Sri Lanka call once again for a comprehensive **positive living intervention** that equips HIV positive people in Sri Lanka with the skills they require to live after being diagnosed with HIV.

The continuum of care is incomplete, and at best reserved only to ART and treatment of OIs. Sri Lanka needs a more holistic approach if HIV positive people are to live with the dignity and rights they deserve, and are to be **advocates for prevention**.

DECISIONS: In the last 12 months, have you done any of the following things because of your HIV status?



77% of respondents decided not to have children because of their HIV status

37% of respondents are intending not to have sex again

56% of respondents are intending not to get married

Rights, Laws, and Policies

Knowledge of laws and policies was poor, and this was predictable. The Stigma Index guidelines suggested we insert the best known national law/policy or set of guidelines, but **Sri Lanka has no laws or policies specifically related to HIV**. The best we could manage was the National Strategic Plan 2007-2011 produced by NSACP, that discusses the need for a policy. 87% of respondents had never heard of it, and only 5% claim to have ever read or discussed it. None of the respondents had ever heard of the Declaration of Commitment on HIV/AIDS made by the General Assembly of the United Nations.

87% of respondents

have never heard of the National Strategic Plan 2007-2011 prepared by NSACP

Only 5% of respondents

have ever read it or discussed it

13% of respondents claimed that they had their rights abused, but only 38% of these (5 respondents) attempted to get legal redress, of which 3 respondents indicated that nothing happened and 2 claimed that the matter was still being dealt with. The research team in discussing issues around laws and policies spoke of how HIV positive people have had poor experiences with HIV and law. They also underlined that people had no confidence in the system and were afraid of being subject to further stigma and discrimination in seeking legal redress for violation of their rights.

If the Stigma Index is to be implemented in the future, we need to consider including knowledge of basic rights, and existing laws and policies under which HIV positive people can find legal recourse. And given that violations continue to occur, as we wait for national policies to be reviewed and adopted, existing laws and policies along with legal teams willing to represent HIV positive people need to be identified, and this information needs to be disseminated across the positive networks.

Effecting Change

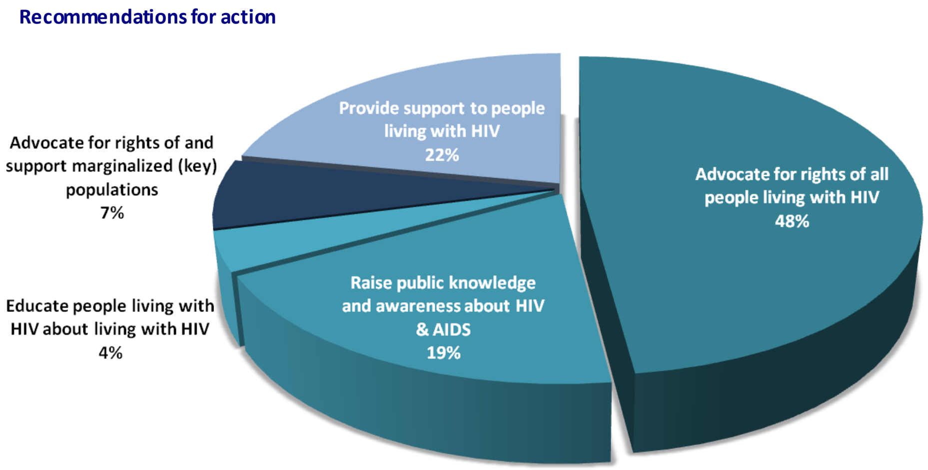
This section in the Stigma Index discusses how HIV positive people can participate in effecting change in their communities. In Sri Lanka the **main obstacle** to effecting change is the **fear of disclosure** and related fears of stigma and discrimination. People are not willing to come forward and be identified as HIV positive. Only certain leaders of the networks do. And while the HIV positive community does feel that they have a stake in effecting change either through policy (5%) or through working on HIV prevention programmes (17%), **47% feel they have no power to influence any decision related to the community**, and prefer to remain silent.

Still, the community, as represented by the Stigma Index respondents, does have recommendations for the HIV industry (Government, Multilaterals, Bi-laterals, INGOs, HIV Business Coalitions, NGOs, and CBOs). Their need assessment is as follows (as discussed with the research team):

- Advocate for our rights, include the rights of marginalized (key) populations.
- We want support, give us skills, jobs, dignity; we don't want handouts.
- Conduct HIV awareness for the public, giving accurate and comprehensive knowledge so that people are no longer scared of us and stop stigmatizing and discriminating against us.
- Teach us how to live with HIV; we don't want to be scared of it any longer.

**"An HIV test is very important.
Although I got infected, I now know how to
protect my wife when we have sex."**

**"Treatment is available free and this is a good thing.
But we need to ensure that we know to take it
without breaking the regime."**



Recommendations

Need for Rights, Law and Policy

Government of Sri Lanka

- Document the legal and rights violations of people living with HIV in Sri Lanka (Human Rights Commission).
- Consider the need for specific law to protect the rights of people living with HIV (Ministry of Justice & Law Reform).
- Establish legal aid services for people living with HIV that include expertise on inheritance property rights, discrimination within healthcare settings and wrongful dismissal under existing laws and policies.

Development Partners

- Advocate with the Government of Sri Lanka for law and policy reform related to the rights of people living with HIV (UN System).
- Convene joint government and civil society forums to highlight and share experiences of good practices globally and regionally in relation to the rights, laws and policies around HIV (UN System).

Civil Society Organizations

- Document experiences of people living with HIV and advocate with the Government of Sri Lanka for their rights.
- Strengthen partnerships and referral systems with government and civil society agencies that provide legal aid services to people living with HIV.
- Develop more effective information, education and communication approaches around existing laws, policies and services so that people living with HIV know and understand their rights and seek legal redress in the event their rights are violated.

Reflections on Health Sector Best Practices

Government of Sri Lanka

- Convene an extraordinary meeting of the National AIDS Committee to share the results of the Stigma Index and provide a forum for discussion on recommendations (NSACP).
- Establish a consultative mechanism to regularly review the continuum of care for people living with HIV (NSACP).
- Strengthen capacity of healthcare professionals in policy and practice relating to rights, confidentiality and testing (NSACP).
- Ensure the rights and confidentiality of potential migrant workers in relation to voluntary counseling and testing (Ministry of External Affairs).
- Strengthen & increase healthcare professionals' knowledge on the sexual and reproductive rights of people living with HIV (NSACP)

Development Partners

- Advocate for consistent Voluntary Confidential Counseling and Testing practices across both government and private sector health care facilities; including private health care facilities for migrant workers (UN System).
- Advocate for consistent approaches across the HIV continuum of care[19] (UN System).

Civil Society Organizations

- Develop strategies to increase knowledge on rights and practices in relation to voluntary confidential counseling and testing services.
- Develop strategies to increase knowledge on sexual and reproductive rights of people living with HIV.
- Strengthen partnerships and referral systems with government and private sector healthcare service providers to encourage a more holistic approach to care and support of people living with HIV.

HIV Prevention Programming

Government of Sri Lanka

- Ensure immediate cessation of 'fear-based' HIV prevention approaches and ensure that future prevention messaging does not contribute to stigma and discrimination of people living with HIV (NSACP).
- Develop guidelines for HIV prevention programming, including IEC/BCC in partnership with people living with HIV to ensure sensitive approaches to HIV prevention programming (NSACP).
- Ensure that a regulatory mechanism is put in place in partnership with Civil Society Organisations to monitor and evaluate HIV prevention programming (NSACP).

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[19] Development of relevant IEC/BCC methodology; provision of condoms; STI management; voluntary confidential counselling and testing; prevention of parent to child transmission; psychosocial support and counselling; treatment and management of opportunistic infections; provision of ART incl. adherence counselling; and palliative care or HIV end stage management.

Development Partners

- Advocate for minimum standards in relation to HIV prevention programming (UN System).
- Convene government and Civil Society forums to share good practices in HIV prevention programming both regionally and globally (UN System).

Civil Society Organizations

- Ensure immediate cessation of 'fear-based' HIV prevention approaches and ensure that future prevention messaging does not contribute to stigma and discrimination of people living with HIV.
- Advocate with the government for minimum standards in relation to HIV prevention programming.
- Develop HIV prevention strategies, including IEC/BCC in consultation with people living with HIV to ensure sensitive approaches to HIV prevention programming.

Greater Involvement of People Living with HIV

Government of Sri Lanka

- Ensure that people living with HIV are actively engaged in the development of the next National Strategy on HIV and AIDS (NSACP).
- Develop specific psychosocial counseling and support programmes for people living with HIV (NSACP).
- Develop a partner/family HIV counseling and testing programme (NSACP).
- Implement the Stigma Index every 2-3 years as a national monitoring tool in terms of measuring country progress in order to reduce stigma and discrimination (NSACP).

Development Partners

- Advocate for the greater involvement of people living with HIV in development of strategic plans and policies related to HIV (UN System).
- Support people living with HIV to gain the skills in order to more fully participate in NAC working groups and other planning forums (UN System).
- Support training of people living with HIV in the development of a framework for positive health, dignity and prevention (UN System).

Civil Society Organizations

- Improve the outreach and services in meeting the needs of people living with HIV and integrating HIV with sexual and reproductive health services.
- Involve people living with HIV in HIV prevention programming and HIV related services.

People Living with HIV

- Strengthen the partnerships between different networks of people living with HIV to advocate as ONE VOICE for the rights and needs of ALL people living with HIV.
- Engage in self-evaluation of strategies and programmes thus far conducted by the networks of people living with HIV to identify good practices that can be replicated and areas where further capacity building is required.

> **"Due to the fear of HIV people are unwilling to come forward to get tested. We need awareness all over Sri Lanka to dispel this ignorance."**

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