

Measuring stigma—building the capacity of networks of people living with HIV to inform policy and practice

Lucy Stackpool-Moore, IPPF; Brianna Harrison, UNAIDS; Christoforos Mallouris, GNP+; Rodrigo Pascal, UNAIDS; and Fiona Pettitt, ICW

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“The People Living with HIV Stigma Index provides the best opportunity for people living with HIV to tell their secrets—so we need to develop the skills to ask them.”

—Princey Mangalika, Lanka+, Sri Lanka (2008)

“Any crystal if processed correctly can become a diamond. The Index has many values and it is up to each individual and country to make the most of it”

—Timur Abdullaev, Uzbekistan (2009)

Within a framework of human rights and development, this paper explores the potential of *The People Living with HIV Stigma Index* as a tool for building the social capital of individuals living with HIV as well as catalysing a broader momentum for social justice, and improved policies and programmes in response to HIV. It is an advocacy and research initiative that is by and for people living with HIV, where the process is just as important as the product. Overall it aims to improve our collective understanding of experiences of stigma, listen to struggles of individuals as they try to achieve their human rights, and document experiences of living with HIV. By putting people living with HIV at the centre of the process, it is an actor-oriented approach to human rights in definition and in process, and as such contributes to the realisation of rights and generation of social capital through the process of working with the tool, as well as through the products that it generates. To date, evidence on stigma has been largely anecdotal, unsystematically gathered, and difficult to compare across populations, socio-cultural and socio-economic issues, and time. *The People Living with HIV Stigma Index* enables the deconstruction of that intangible entity – stigma – through documenting the experiences of individuals in a process that is not only nationally grounded and relevant, but also internationally comparable.

Addressing stigma and promoting human rights—Cornerstones of an effective responses to HIV

Stigma limits access to health services by silencing discussions about sensitive issues that are integral to HIV vulnerability — such as race, poverty, gender relations, gender imbalances, sexuality and drug

use (Morrison, 2006; Parker and Aggleton, 2002). Stigma reveals itself not only in issues that are sensationalised or reported inaccurately, but also in what is left unsaid and in voices that are not heard. It is both what is talked about and how, as well as what is silenced and why, that fuel this vicious cycle linking stigma to marginalization and vulnerability to human rights violations. Much of what we know about the stigma attached to HIV, and the resulting discrimination towards people living with the virus,¹ is anecdotal or fragmented. Existing surveys show that while much is known about the influence of HIV-related stigma there is no clear picture of its actual magnitude or complexity, nor do we have the tools that enable the comparison of experiences and instances of stigma across many domains (Nyblade and MacQuarrie, 2006).

Discrimination on the grounds of HIV status is a violation of human rights². Moreover, stigma and discrimination against people associated with or living with HIV impacts all areas of life and is often cited as one of the primary hurdles in addressing prevention and care issues, and as a stumbling block in ensuring access to essential services (Brouard and Wills, 2006; APN+, 2004).³ In many countries this can particularly affect women as they are often diagnosed earlier than men and have more interaction with health care professionals, particularly in relation to reproductive health. Without concerted action to eliminate stigma, the goal of universal access to these vital services will be impossible to achieve (DfID, 2007; Clay et al., 2007; Kidd and Slay, 2003). Stigma often builds upon and reinforces other existing prejudices, such as those related to gender, sexual orientation, behaviour and race. Despite all we have learned over the past twenty years about HIV-related stigma, it continues to result in acts of discrimination, and hampers access to vital services, including testing, and is a fundamental human rights concern.

It is all too often assumed that stigma is directly related only to the HIV-positive status of an individual, but key vulnerable populations such as sex workers, men who have sex with men, injecting drug users, and young women and girls, often face compounded stigma due to pre-existing attitudes relating to homophobia, the buying or selling of sex, and/or to drug use. There is also stigma by association resulting from assumptions that all people living with HIV are part of a vulnerable group when this is not always the case. Fundamentally the response to HIV must have an impact at two levels – the individual, where the realities of having to live, love, and work in the context of the epidemic need to be internalised; and the environmental, where these principles are not in conflict but are supported by external realities of equality and acceptance, rather than inequality and intolerance.

¹ **Stigma** is a process of producing and reproducing inequitable power relations, where negative attitudes towards a group of people, on the basis of particular attributes such as their HIV status, gender, sexuality or behaviour, are created and sustained to legitimize dominant groups in society. The stigma associated with HIV is often based upon the association of HIV with already marginalized and stigmatized behaviours, such as sex work, drug use and same-sex and transgender sexual practices. Stigma relating to HIV affects people living with HIV and — through association — their partners, children, households and others in their communities. **Internal or self stigma** refers to the way a person living with HIV feels about themselves and specifically if they feel a sense of shame about being HIV positive. Internal stigma can lead to low self-esteem, depression or can result in a person living with HIV withdrawing from social and intimate contact. **Discrimination** is a manifestation of stigma. Discrimination consists of actions (or lack of actions) directed towards individuals who are stigmatized. Discrimination occurs at many different levels, for example within a family or community setting, in an institutional or educational setting, and/or in national policies or laws. (These definitions are taken from GNP+ and the Asia-Pacific Network of People Living with HIV (ANP+), *NGO Code of Good Practice: Self-Assessment Checklist: Stigma and Discrimination*, at www.hivcode.org/silo/files/stigma--discrimination-.pdf.)

² See, *inter alia*, Commission on Human Rights resolutions 1995/44 of 3 March 1995 and 1996/43 of 19 April 1996.

³ National governments in nearly all countries (98%) report addressing stigma and discrimination as part of their national HIV strategy, including all countries with a generalized HIV epidemic reporting this data (UNGASS Country Progress Reports, 2008, cited in UNAIDS, 2008 Report on the Global AIDS Epidemic, p 81).

Mobilising individual and social capital: Putting people living with HIV at the centre of the research process

To fill the gap in our global understanding and build an evidence base to inform policy and practice, *The People Living with HIV Stigma Index*⁴ is a new research initiative to measure stigma, by and for people living with HIV. It has been developed and is the result of a partnership between the International Planned Parenthood Federation (IPPF), two networks of people living with HIV: the Global Network of People Living with HIV (GNP+) and the International Community of Women living with HIV (ICW), and The Joint United Nations Programme on HIV/AIDS (UNAIDS). To date the global initiative has received financial support from GTZ (the German international technical cooperation agency), UNAIDS and the (U.K.) Department for International Development (DfID), with the key objectives of increasing advocacy and building the evidence base; and operationalizing the Greater Involvement of People Living with HIV (GIPA).⁵ The rigorous quantitative and qualitative research conducted will enable better informed policies, more effective programmes and will be an empowering experience for the people living with HIV involved in the process. It will generate a wide range of knowledge and best practices that the partners will collect and disseminate at the national and international level.

“Finally we will be able to evaluate levels of stigma and discrimination in our country. *The People Living with HIV Stigma Index* is the only tool we have to show how stigma is a fact of life”

—Workshop participant, Belarus (2009)

“I have spoken out against stigma. But I have been struggling with the evidence to quantify it. As a researcher and as an advocate I now have the missing link.”

— Beatrice Were, Uganda (2008)

The tool has been developed to help measure stigma and discrimination, to measure the impact of our interventions, and to document the well-being of people living with HIV over time. Some of the key areas explored in the research include the causes of stigma and discrimination; access to work and services; internal stigma; rights, laws and policies; effecting change; disclosure and confidentiality, treatment; having children; and overcoming stigma.

Specifically, the expected results of *The People Living with HIV Stigma Index* include:

- 1) Evidence to improve policies** and ensure that policies are grounded in the realities of living with HIV. The findings will be used to promote the human rights of people living with HIV and advocate for policy change on key legal, health and other issues
- 2) Improved programs influenced by the perspectives of people living with HIV** to better meet the needs of people living with HIV and increased access to, and uptake of, services

⁴ See www.stigmaindex.org

⁵ See UNAIDS (2007). *Policy Brief: The Greater Involvement of People Living with HIV (GIPA)*.
http://data.unaids.org/pub/BriefingNote/2007/JC1299_Policy_Brief_GIPA.pdf

3) Models of best practice for the greater involvement of people living with HIV (GIPA) by putting people living with HIV at the centre of the process and ensuring that it remains by, and for, people living with HIV throughout all stages of implementation

In essence therefore, successful roll out of the Index necessitates the capacity development of people living with HIV to lead the process—and to build strategic partnerships to support them. Specific standards have been developed to assist the networks of people living with HIV achieve this in their country (see annex 1). In other words, the *People Living with HIV Stigma Index* is a tool designed to contribute to mobilising individuals and networks of people living with HIV to measure and advocate for better efforts to address stigma while also catalysing momentum in the wider political and social response to HIV and addressing stigma in a particular national context.

The primary research tool for *The People Living with HIV Stigma Index* is a questionnaire that is divided into three main sections to measure stigma and discrimination, covering perceptions of self and internal stigma as well as specific examples of stigma or discrimination in different settings such as the home, community, workplace, religious or health care setting. All participants are asked to respond to the questions based on their experiences in the last 12 months, and the findings from Index in any one country will provide a snapshot for that moment in time (e.g. in the Dominican Republic, in 2008). For this period in time, the findings could be triangulated with the Demographic Health Survey (DHS) or other national studies of perceptions of HIV and stigma (notably that do not explicitly include the perspectives of people living with HIV) to analyse the trends and incidence of HIV related stigma and discrimination in that time period. The first rollout of *The People Living with HIV Stigma Index* in a country will provide a baseline for future comparison, for example when it is subsequently rolled out again in two or three year intervals (e.g. the Dominican Republic in 2008, 2010 and 2012). In so doing, the Index will be a useful tool for comparing changes in trends in specific key populations, changes in trends of HIV-related stigma and discrimination experienced in specific locations (for example in the workplace, a community setting, or a health clinic), or changes in knowledge, awareness and use of laws and policies to protect the rights of people living with HIV. Subsequent rollout of the Index will also provide opportunities to further develop the capacity of some of the original researchers and networks of people living with HIV involved in the work with the Index. By measuring the complex dimensions of HIV related stigma and discrimination, *The People Living with HIV Stigma Index* will provide an important piece of a complicated puzzle to measure the nuances and changes over time and be a useful resource for analysing what is and is not working in national responses to HIV.

“People are really keen to implement the index because they recognize it has been created by and for positive people, and that it can ultimately benefit their communities.”

– Kate Thomson, Chief of Civil Society Partnership Team, UNAIDS (2008)

The process includes referrals (to a variety of services, materials and sources of support) and follow-up support for all involved. The interviewers are people living with HIV themselves, interviewing other people living with HIV, and they adopt a ‘side-by-side’ approach in the interview to make it as comfortable, empathetic and empowering as possible. Like other research studies, *The People Living with HIV Stigma Index* must observe certain standards with regard to ethical issues and data protection. In each country where this survey is carried out, those responsible for conducting the study ensure that it conforms to that country’s ethical and data protection requirements. Two issues

of particular importance are informed consent (every person interviewed must be fully informed about the nature of the study and then give their consent); and confidentiality (ensuring that the information participants have disclosed and their identity are kept in confidence). Working with the tool as an initiative that is by and for people living with HIV can be just as significant as the results for understanding the legal, political and social context of living with HIV. Participants learn firsthand about their rights - such as the right to privacy – through learning about how and why *The People Living with HIV Stigma Index* process respects and protects, or measures, those rights.

“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 phase, South Africa (2006)

The research findings and follow-up case studies will be used to advocate for evidence based policy and practice that is grounded in the real experiences and perspectives of people living with HIV. The country level advocacy plan is part of the country roll out and led by people living with HIV. It is supported by regional and global advocacy led by the wider partnership. Findings from the initial country rollout and discussion with the in-country teams indicate that the process of the research is just as significant as the results for measuring--and contribute towards addressing--the stigma experienced by people living with HIV.

After the tool was finalised in 2006, incorporating findings from the pilot process,⁶ the focus has been on developing the necessary global systems and structures to support the subsequent national research with *The People Living with HIV Stigma Index*. Regional workshops conducted in 2008/9 to build the capacity of national networks of people living with HIV to rollout the Index in their respective countries. To date, 128 people have been trained in 7 regional workshops, from more than 90 organisations and 69 different countries in Asia, the Pacific, Africa, Latin America and the Caribbean, North Africa and the Middle East, and Eastern Europe.⁷ To support follow-up after each of the regional workshops, the country teams can apply for seed grants (USD \$2,000) to catalyse the partnership development and resources mobilisation for the national rollout of *The People Living with HIV Stigma Index* in their country. To apply for a seed grant, the country teams submitted a short proposal that includes a clear articulation of the overall goal for working with the Index in a country, and then specifically for working with the seed grant including identifying and mobilising partners (strategic ones – including a research institution), raising awareness among other stakeholders about the research (e.g. National AIDS Councils, government departments, civil society), mobilising resources, working with a range of networks or organisations of people living with HIV. GNP+, IPPF, UNAIDS and ICW continue to work closely together to administer the seed grants and to date 23 proposals have been accepted and are at different stages of completion (Burundi, Bangladesh, Cameroon, Ecuador, Fiji, Haiti, India, Malawi, Malaysia, Mexico, Myanmar, Nepal, Niger, Pakistan, Papua New Guinea, Sri Lanka, Argentina, Colombia, Congo, El Salvador, Panama, Paraguay, Thailand).

⁶ *The People Living with HIV Stigma Index* was piloted in five countries (Kenya, Lesotho, Trinidad and Tobago, India and South Africa) in 2006 and in Georgia in 2008. The first full national rollout was in the Dominican Republic in 2008 where a team of researchers from two of the national networks of people living with HIV (ASOLSIDA and REDOVII) have been working alongside Profamilia (the national family planning association) and the Institute for Population and Development Studies to carry out the research.

⁷ The International Partners also aspire to conduct a regional rollout in Western and Southern Europe later in 2009, and additional funds are currently being sought to support this.

The following section situates this unique tool within a broader framework of development, social mobilisation, and processes of documenting the barriers and opportunities to the realisation of human rights relating to stigma and discrimination in the context of HIV.

Building social capital—realising human rights

Development can be defined as a process of expanding the freedoms, choices and opportunities that people enjoy (Sen, 1999; Stiglitz, 2002; Schumacher, 1973). This definition of development underpins the approach of *The People Living with HIV Stigma Index*, which aims to build the capacity of non-traditional researchers (networks of people living with HIV) to conduct credible research, to advocate effectively based on the results, and to benefit from the process of doing the research. In a similar vein, human rights have been argued as being essential for promoting human security and national development (Duffield, 2007). Health, education and other (intangible) social resources are essential for empowering citizens, achieving national development and economic growth (Braveman and Gruskin, 2003).

During the last 20 years or so development has evolved from being something that is ‘done to’ poor countries and poor people to something that is often facilitated, enabled or ‘done with’. This period has seen a shift in development towards a more participatory approach grounded in the realities of individuals and communities (Chambers, 1997).⁸ The onset and increasing popularity of participatory approaches to development have marked a shift in practice as well as a shift in ideology, looking more to the most affected individuals and communities to be the central actors driving the development process. As such, it has led to an increased recognition of the perspectives, voices and realities of people most deprived of development—poor or marginalised people—in shaping and leading the process of development (Chambers, 1997). Participation draws on Freirean notions of self-critical awareness (*conscientização*) and a belief that “reflection—true reflection—leads to action” and that ‘oppressed’ people themselves hold the key to their own development and sustainable social change (Freire, 1972, 48; Freire, 1974). The most significant contribution of the participation movement to date is found less in the practical tools and approaches it espouses and more in the recognition of the agency and integral role that actors have in their own development and processes of change.

This shift towards *actor*-oriented approaches to development is mirrored in the evolution of human rights. Modern concepts of human rights build from the natural, individual and communal sources of rights and espouse the rights of the individual within a symbiotic relationship with the rights of others, and also include an implicit recognition of the obligations (individual and state) necessary to achieve them. They take into account the differences between civil and political rights and economic and social rights, but ultimately recognise all as indivisible and interdependent (Donnelly, 2003).

Increasingly, human rights have been reframed as ‘shaped through actual struggles informed by people’s own understandings of what they are justly entitled to’ (Nyamu-Musembi, 2002, 1). This definition does not contradict but rather expands more traditional definitions of human rights which have already articulated the role of human rights principles in achieving equal opportunities in health and other aspects for people who have historically suffered discrimination or social marginalization (Braveman and Gruskin, 2003). Human Rights-Based Approaches to development were formalised in international documents such as the Human Development Report (2000) and the 2003 Statement of Common Understanding amongst UN agencies of the principles.⁹

⁸ The fundamental principles can be summarised into three main points: (1) Outsiders facilitate not dominate; (2) Methods indicate a shift from closed to open, individual to group, verbal to visual, measuring to comparing; (3) Partnerships and sharing of information – between insiders and outsiders, and between organisations (Chambers, 1997, p 105-106).

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All of the above definitions imply that to effectively promote human rights—and in this example to address stigma and discrimination relating to HIV infection and vulnerability—interventions need to focus equally on the individual (and all the associated murkiness and inconsistencies of the contested identities and one life) and the environment (and all the associated complexities and competing priorities of many lives). All human rights—economic, social, cultural, civil and political—are considered interdependent and indivisible.¹⁰ They also necessarily link the individual with the wider social context, as the quest for universality in the realisation of human rights necessitates the realisation of those rights for each individual in the world across borders. As noted in an exposition of HIV, health and human rights in Haiti, Paul Farmer notes how this integration of rights is obvious: “when we look at and listen to those whose rights are being trampled, we see how political rights are intertwined with social and economic rights, or, rather, how the absence of social and economic power empties political rights of their substance” (Farmer, 2005, 16-7).

Significantly, and perhaps ahead of their time, the international declarations articulate the holistic nature of the right to health for example and highlight how it cuts across many facets of development and human rights.¹¹ Realising the right to the highest attainable standard of health necessitates a comprehensive approach that incorporates promoting rights to education, information, privacy, decent living and working conditions, participation, and freedom from discrimination (Braveman and Gruskin, 2003).¹² The definition of the right to the highest attainable standard of health unequivocally places human rights at the core of any national or international response to HIV, while also articulating how all-encompassing and complex the realisation of this right is for individuals and for societies.

Therefore central to the realisation of the human right to the highest attainable standard of health is a complex and holistic process of participation that supports individual change while also transforming social determinants of health. The *International Guidelines on HIV/AIDS and Human Rights* explicitly articulate the importance of the right to participation in a rights-based response to HIV: “Realization of the right to take part in the conduct of public affairs, as well as in cultural life, is essential to guaranteeing participation by those most affected by HIV in the development and implementation of HIV-related policies and programmes”¹³. These principles of participation and human rights in the response to HIV were crystallised in 1994 with the articulation of the GIPA Principle—the Greater Involvement of People Living with HIV.¹⁴ The Greater Involvement of People living with HIV/AIDS is “a principle that aims to realize the rights and responsibilities of people living with HIV, including their right to self-determination and participation in decision-making processes that affect their lives. In these efforts, GIPA also aims to enhance the quality and effectiveness of the AIDS response.”¹⁵ *The People Living with HIV Stigma Index* is GIPA in action; it applies the principle to

¹⁰ See the Universal Declaration of Human Rights (1948), the International Covenant on Economic, Social and Cultural Rights (1966) and the International Covenant on Civil and Political Rights (1966).

¹¹ The right to the highest attainable standard of health as a ‘state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity’ as ‘one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition’ was recognised in 1946 with the adoption of the Constitution of the World Health Organisation and echoed two years later in article 25 (1) of the Universal Declaration of Human Rights (UDHR) and again article 12 of the International Covenant of Economic, Social and Cultural Rights (ICESCR) in 1966.

¹² Article 3 of the ICESCR refers to certain other human rights as ‘integral components’ of the right to health. Article 11 of this Comment also refers specifically to participation: “A further important aspect is the participation of the population in all health-related decision-making at the community, national and international levels.”

¹³ UNAIDS and OHCHR (2006) *International Guidelines on HIV/AIDS and Human Rights*, p. 99..

¹⁴ The idea that the personal experiences of people living with HIV could and should be translated into helping to shape a response to the AIDS epidemic was first voiced in 1983 at a national AIDS conference in the USA. It was formally adopted as a principle at the Paris AIDS Summit in 1994, where 42 countries declared the Greater Involvement of People Living with HIV and AIDS (GIPA) to be critical to ethical and effective national responses to the epidemic. See www.unaids.org/en/PolicyAndPractice/GIPA/default.asp

¹⁵ UNAIDS (2007) *Policy Brief: Greater Involvement of People Living with HIV/AIDS*. Accessed on 3 March 2009 at: http://data.unaids.org/pub/Report/2007/JC1299-PolicyBrief-GIPA_en.pdf

the collection of data and measurement of the experiences of people living with HIV and groups vulnerable to HIV, as well as the design of advocacy strategies employing the results of the Index.

Within this framework, this paper explores the potential of *The People Living with HIV Stigma Index* as a tool for putting people living with HIV at the centre of the research process to more effectively understand stigma and discrimination relating to HIV. As an initiative by and for people living with HIV, it is an actor-oriented approach to human rights in definition and in process, and as such strives to contribute to realising rights and generating social capital from the process of working with the tool as well as from the products that it generates. This paper explores how the process of measuring HIV related stigma and discrimination—a research and advocacy initiative that builds the capacity of people living with HIV to drive the research—can catalyse the realisation of human rights and can generate momentum for change for the individual as well as for the wider environment.

Who counts reality?

Documenting HIV-related stigma and making a link to human rights

Processes of documenting human rights, and recent changes that shift the spotlight of legitimacy towards self-reporting and self-representation of experiences and struggles to realise human rights, highlight how the process can itself contribute to development and the realisation of human rights.

Traditionally, the dominant mode of witnessing the human rights violations experienced by individuals has been through third parties documenting and reporting cases where violations have occurred. Historically, the independence and objectivity of the person doing the documenting has been sought to give validity and credibility to the testimony. For example Amnesty International (AI), a membership based campaigning organisation for human rights, asserts the importance of being independent, autonomous and democratic and describes its mission 'to conduct research and generate action to prevent and end grave abuses of human rights'. AI tends not to employ someone from the country under investigation to research suspected human rights violations in that country.¹⁶ In these cases, the impartiality of the testimonies (and the process involved in collecting the testimonies) is championed as the cornerstone of their legitimacy.

One may argue that such approaches can entrench existing power inequalities (for example between well educated, foreign and often Western human rights researchers and often disenfranchised, localised communities) and may lead to the misrepresentation of the voices of those already underrepresented (Slim and Thomson, 1993). Erica Burman examines these issues specifically in relation to representations of women's voices within prevailing processes of power (Burman, 2004). She argues that often their perspectives are 'feminised' to domesticate and normalise the prevailing inequalities, exploitations and oppression of women which is very distant from the actual embodied, thinking and real women. Burman builds on other feminist critiques such as Judith Butler and argues for due recognition to be given to power relations, subjectivity and agency in the witnessing process (cf Butler, 1997). Burman contests the appropriation of women's voices and problematises the status and function of such processes of representation. The feminist and participation critiques of the process of witnessing therefore illustrate the necessity to bring about a shift in recognition of whose perspectives count and who is able to extract or give (see further elaboration below) the most legitimate account of human rights violations. Where there are competing interests or contested perspectives, the question becomes not one of legitimacy but rather one of gathering a diversity of voices.

¹⁶ Form the Amnesty International website www.amnesty.org accessed on 5 January 2009 and from pers comm, AI researcher.

It seems, therefore, that there are at least two ways of ‘bearing witness’: reporting and experiencing (Farmer, 2005). Organisations such as Amnesty International (AI), Human Rights Watch (HRW) and other human rights advocates have been documenting and reporting human rights violations that are occurring in different corners of the world. In so doing, they have no doubt shifted the spotlight onto communities and people who may otherwise never have been seen or championed on the world stage. Their work, and the proliferation of human rights principles fostered by that work, have generated an ‘advocacy revolution’ which in itself has given bystanders, witnesses, and the survivors of human rights abuses unprecedented recognition and added credibility to their daily struggles (Ignatieff, 2000). But it is essential that these observations are not blinded in the pursuit of objectivity. Burman further urges those reporting to be aware of their own role in constructing or framing the voices they present and to interrogate what the mediating reporter is doing with the testimonies and why (2004). The subjectivity (and often empathy) of the reporter is also emphasised by Paul Farmer, an anthropologist and medical doctor who has worked extensively with people living with HIV in Haiti: “Bearing witness is done on behalf of others, for their sake (even if those are dead and forgotten). It needs to be done, but there is no point exaggerating the importance of the deed ... no matter how great the pain of bearing witness, it will never be as great as the pain of those who endure, whether in silence or with cries, the indignities described” (Farmer, 2005, 28). For Farmer, bearing witness is not objective and complete, but rather partial accounts of an eye witness, based on compassion and solidarity. Perhaps, therefore, the notion of the objective witness is illusory and impossible to separate from the empathetic, human witness who is always blinkered by self-constructed views and perceptions of their own reality.

The shift towards recognition of the role of the witness in the construction of the experience reported facilitates valuing not only direct experiences of human rights, but also self-represented descriptions of those experiences as legitimate mechanisms for documenting human rights violations and realities. The process for documenting human rights realities (including success stories and realisation of rights as well as violations) becomes just as important as the product or final testimony (Uvin, 2004; Nyamu-Musembi, 2002). Although these will always remain liable to criticism for bias and self-promotion (of groups or individuals), they gain strength from the validity of being unmediated testimonies of people most affected by a human rights issue. There is no lens through which their words are filtered; the voices speak for themselves thus reducing the risk of direct misrepresentation.¹⁷ Some examples include the oral testimony (OT) approach developed by Panos London that trains people to interview their peers using a life history methodology (Panos, 1999; Slim and Thompson, 1993). In this process the microphone and recording equipment have literally been handed over to affected communities to document their own experiences and perceptions about the specific issue. The OT methodology has been applied in many different contexts and to a range of human rights issues such as access to water, civic participation, and the right to the highest attainable standard of health.¹⁸ The eloquence and directness that the voices of the people themselves can be further enhanced by the use of visual images (McLagan, 2006). Other examples have engaged more fully with new communication technologies and are working with participatory video (such as INSIGHT) and other online medium (see WITNESS) to similarly collect snapshots and testimonies that are self-reported by people most affected by a particular issue.¹⁹ In a similar vein to some of the methodologies described above, *The People Living with HIV Stigma Index* is a new tool which enables self-represented descriptions of violations of human rights specifically in the context of HIV and AIDS.

¹⁷ However of course this risk remains when the testimonies are used in part or in full and reframed as part of advocacy campaigns or other uses.

¹⁸ See www.panos.org.uk for details of the full collections

¹⁹ For further details see INSIGHT (www.insightshare.org/index.html) and WITNESS (www.witness.org/)

A country example: Documenting stigma and discrimination experienced by people and living with HIV in the Dominican Republic

HIV provides an exceptional opportunity to interrogate the extent to which the right to health and other human rights such as the right to non-discrimination, access to information, and participation in political and cultural life are being realised. As an epidemic that thrives among people at the centre of social inequities and injustices—for example among men who have sex with men, sex workers, people who inject drugs, and women who may find it difficult to negotiate the use of condoms—the experience of those living with HIV can provide litmus test for how governments and societies are promoting the human rights of those who are often the most marginalised and arguably therefore the most in need of protection. Peter Piot, the former Executive Director of UNAIDS, argued that HIV calls for an exceptional response for an unprecedented crisis—a response that has human rights principles at its core and promotes development, empowerment and the realisation of those rights for all, especially those most marginalised and at risk of infection (Piot, 2003).

‘While rights to happy, healthy and safe sex and reproduction are enshrined in international law, reality is very different. Realizing those rights requires new ways of addressing old problems—approaches that can help to bring about the deeper personal, societal and professional transformations necessary for real change. It calls for strategies that enable people to realise that they have rights, to recognise and act on what they feel they are owed by their partners and communities, as well as by the state; it equally requires building responsibility and responsiveness.’

(Cornwall and Welbourn, 2002, 2)

From a human rights perspective, HIV provides a lens through which to examine whether people have freedom to implement HIV preventative practices; freedom from stigma, discrimination and violence; and opportunity to cultivate human capital and economic growth. HIV has turned the spotlight on the realisation (or lack of) of human rights, and the language of human rights and the weight of the international declarations underpins global as well as many national and community responses to the epidemic (ICASO, 2002; Bloom and Canning, 2003; UNGASS, 2001).

The Dominican Republic provides a unique and interesting example to explore these issues because recent reports have explicitly focused on documenting the human rights realities of living with HIV—having adopted very different methods of documenting human rights violations. The Dominican Republic shares an island with Haiti and situated in the Caribbean. In 2007 it was estimated that 65,000 adults and children are living with HIV—approximately 1.1% of the adult population (UNAIDS, 2008). According to UNAIDS, in 2007 approximately 38% of people living with HIV and who need Anti-Retroviral Therapy (ART) are receiving this, which is an increase from 5% in 2004 (UNAIDS, 2008). However less than one third of people who needed it were receiving ART in 2006 (AI, 2006).²⁰ One of the main drivers of the epidemic in the Dominican Republic is the entrenched inequality between men and women and significant levels of high-risk behaviour, such as low condom use, multiple sex partners, and early sexual activity (HRW, 2004). As the HRW report states, ‘the government has failed to take seriously the link—well-established and analysed in international public health and human rights literature—between the spread of the disease and entrenched sex inequality, violence against women, and social biases that otherwise limit women’s autonomy and rights’ (HRW, 2004, 2). As a signatory of the Universal Declaration of Human Rights (UDHR), and party to the International Covenant on Economic, Social and Cultural Rights (ICESCR) and other

²⁰ Based on correspondence with DIGECITSS (Dirección General de Control de las Infecciones de Transmisión Sexual y SIDA) and UNAIDS data, AI found that 2,700 people living with HIV were receiving ART of an estimated 10-15,000 who needed it (p 17-8).

international declarations such as the UN General Assembly Special Session on HIV/AIDS (UNGASS) Declaration of Commitment, the Dominican Republic is legally bound to implement the human rights recognised in those documents.²¹ The Dominican Republic is therefore required to implement (i.e. respect, protect and fulfil) a range of rights including the right to the highest attainable standard of health, the right to privacy, and non-discrimination on the basis of sex or health status (such as HIV status). In 1996 *Ley 55-93 Sobre el SIDA* (Law 5593)²² was passed in order to better protect the rights of people living with HIV in the Dominican Republic and to translate some of the international declarations into national law. Whilst on paper the law is designed in principle protect the rights of people living with HIV, it is reported to have had very limited purchase (Profamilia *et al*, pending; AI, 2006). Even though the right to health is subject to progressive realisation, and so States are not required to immediately achieve the goal of highest attainable standard of health, other related rights such as non-discrimination are subject to immediate implementation. Overall it seems that to date the government response could do more to effectively promote non-discrimination relating to HIV and to address the underlying social inequalities in which HIV flourishes.

Human Rights Watch (HRW) conducted research in 2004, and Amnesty International (AI) in 2006, looking specifically at the experiences of people living with HIV in the Dominican Republic. The HRW report focused specifically on women, with key findings relating to experiences of discrimination in health care settings and unfair dismissal and discrimination in the workplace for women (2004). The AI report focused on key human rights issues such as the right to health, access to essential medicines and health care, and the right to privacy. Both reports documented significant experiences of discrimination for people living with HIV, particularly in the workplace; documented violations of the right to privacy and a lack of confidentiality regarding disclosing HIV status in health care and other settings; and the stigmatisation and violence against women living with HIV. In 2009, the findings of another study focusing on human rights, women and gender violence and living with HIV in the Dominican Republic were published (Profamilia *et al*, pending). However, the methodology of this research differed significantly from the HRW and AI research in that it adopted a participatory and actor-oriented approach to the information gathering and documentation process and was the first country to rollout *The People Living with HIV Stigma Index*.

Research was undertaken by a partnership between Profamilia, the Institute of Population and Development Studies (IEPD), and two national networks of people living with HIV—ASOLSIDA and REDOVIIH between December 2007 and 2008. A total of 1000 people were interviewed in four different geographical areas, covering a mix of urban and more rural settings. A total of 510 women, 486 men and 4 transgender participated in the study. To ensure that the Index was most relevant to the pressing issues in the Dominican Republic, *The People Living with HIV Stigma Index* questionnaire also included supplementary questions which included a special focus on women, gender violence and young girls.

The main findings from the national rollout have included those relating to the process of working with the Index and those specific to the outcomes or findings of the research (IPPF, GNP+, ICW, UNAIDS, 2008a). These included forging new partnerships and raising awareness of HIV and human rights through the outreach process of peer-interviewing; as well as documenting experiences of stigma and discrimination in the workplace, experiences of gender violence and blame for women living with HIV, discrimination in health care settings such as forced sterilisation, and a lack of familiarity and invocation of Law 5593 (Profamilia *et al*, pending). 73.3% of women and 64.8% men knew about the Law 55-93 on HIV and AIDS. Almost one in four people interviewed (23.1%)

²¹ Other relevant treaties include CRC, CEDAW, the UN Convention on the Elimination of All Forms of Racial Discrimination and the Additional Protocol to the American Convention on Human Rights (the San Salvador Protocol).

²² See www.suprema.gov.do/pdf/leyes/1993/ley_55-93.pdf

reported a violation of their human rights as a person living with HIV in the last 12 months and only 10% tried to readdress this situation. The project leaders will use the findings to support the advocacy of ASOLSIDA and REDOVIIH and will inform the review process of the national law to protect the rights of people living with HIV that is planned for 2009.

“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”

Stigma Index co-coordinator, 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”

Stigma Index researcher, June 2008
(IPPF, 2008a)

Even though Law 5593 was established to protect the rights of people living with HIV, and to nationally legislate the principles of the international declarations, *The People Living with HIV Stigma Index* found that few people living with HIV have heard of the Law and even fewer have used it to achieve legal address where their rights have been violated (Profamilia *et al.*, pending; IPPF, 2008a; AI, 2006; HRW, 2004). This is an interesting finding, since it was a key advocacy point identified by Human Rights Watch in 2004. It seems little had changed by the time Amnesty conducted its research in 2006. Both the HRW and AI reports were compiled by external researchers interviewing people living with HIV, accompanied and guided by local partners (HRW, 2004; AI, 2006). Yet by 2008, despite the robust and persuasive research reports drawing attention to this issue, it seemed that still little had changed when *The People Living with HIV Stigma Index* was implemented—many people living with HIV were still not familiar with the provisions of the law or how to use it to invoke redress for their experiences of discrimination (Profamilia *et al.*, pending). The findings from the Index will be incorporated into civil society advocacy to inform the law review process in 2009 and will call for Law 5593 to more effectively protect the rights of people living with HIV. The advocacy and process of working with the Index research will create one channel for the voices of people living with HIV to actively engage with the law review process. Beyond advocacy, the process of working with the Index aims also to have enhanced the awareness of human rights, legal and peer-support available for people living with HIV who will subsequently be better equipped to claim those rights in the future. It is hoped that the capacity development and empowering process associated with the implementation of *The People Living with HIV Stigma Index* might mean that by 2010, if further human rights research is undertaken, changes will in fact be seen in levels of awareness of, and claims made under Law 5593. One way to measure whether this impact has been achieved would be to implement the Stigma Index again in 2010.

Some preliminary outcomes and findings from the implementation of the Index in the Dominican Republic include:

- **Evidence to improve 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
- **Stronger partnerships** between networks of people living with HIV (leading the process), UN agencies, national family planning associations and research institutes resulted from the implementation of the Index

- **Raising awareness about HIV stigma:** The process of conducting in the interviews has enabled the sharing of information about rights, laws and policies relating to HIV stigma among people who may not otherwise have heard of them. It also strengthens the outreach and relationship between the core research team and others in the national networks of people living with HIV
- **Supporting People Living with HIV:** The research shows that support for the interviewees 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 People Living with HIV Stigma Index* is a 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. Qualitative case studies and life stories can complement the findings of the Index and strengthen the research process and outcomes

Conclusion

“The Index will help us document our own experiences and strengthen our advocacy work. This is a way that we can start to change the conversation—we will have the evidence to back us up.”

—Anan, Thai Network of People Living with HIV (2008)

In this paper we have argued that the process of recording can be just as significant as the product for having an impact for the individual itself as well as for the wider social environment. Human rights gains can result simply from meaningfully involving people most affected in the process of documenting their experiences (or lack of) of their human rights. The early findings from the Index (and the case study from the Dominican Republic) measure the extent to which human rights are being realised by people living with HIV and also measure the extent to which existing measures (e.g. laws) are effective in supporting the realisation of those rights. Development and human rights are concepts that stretch across the diverse complexities of individual people living through daily realities in different environments. Both concepts are all-encompassing, built on pillars of freedom, agency and human capability—and *The People Living with HIV Stigma Index* illustrates an example of how the process of measuring can in itself contribute towards the realisation of human rights. In other, the Index illustrates how the mobilisation of social capital of individuals and networks of people living with HIV to document human rights can itself contribute towards a shift in the wider social and economic environment by recognising and documenting the nuances and complex layers of stigma relating to HIV, by generating dialogue based on the perspectives of people living with HIV, and by using that evidence to inform more effective policies and programmes.

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Annex 1



STANDARDS FOR COUNTRY ROLLOUT *The People Living with HIV Stigma Index:*

This document outlines practical ways to ensure that in practice, the implementation of the *People Living with HIV Stigma Index* (the 'Index') remains true to the ethos that it is an initiative by and for people living with HIV. It provides good practice standards to guide country teams rollout the index in their country. These Standards, the User Guide and related Index documents are intended to ensure that the Index is implemented in accordance with the principles of a human rights-based approach.

1) NATIONAL PARTNERSHIP RESPONSIBLE FOR IMPLEMENTING THE INDEX

- The national partnership should be driven by people living with HIV networks, ensuring full participation of people living with HIV throughout the process of implementation, including building the partnership, strategically planning for the implementation, budgeting and resource allocation, research and data analysis, monitoring, evaluation, communicating the research results and other advocacy.
- Representatives from UNAIDS, IPPF, the national partners of ICW and GNP+, and government representatives and civil society organizations should be involved in the planning stages for the index and be active in the partnership and implementation as agreed and appropriate. Other partners should be identified as appropriate to support the specific needs of each country implementation plan.
- Each national partnership should include a research partner (e.g. an academic Institution)
- Multisector government participation is recommended in the national partnership, and involved as appropriate in the planning, implementation and reporting about the index. The national AIDS council and ministries responsible for health, human rights, education and other related areas could be included in information meetings, reviewing project proposals and research dissemination activities. Interested multilateral and bilateral donor agencies should also be included.

2) METHODOLOGY

- The questionnaire should not be changed or adapted.
- Additional sections could be added as required by national partnership to focus on specific issues such as specific themes (e.g. gender violence), key populations (e.g. MSM), accessing services (e.g. experiences in different health care settings), and/or cultural needs (e.g. religion).
- The national partnership should ensure that support (logistical, emotional, technical) is provided to the interviewers involved in the research
- The national partnership should ensure that appropriate referrals, follow-up and support are provided to the participants in the research, particularly interviewees and interviewers.
- Each national partnership should seek to develop qualitative work to compliment the work with the index, in consultation with the international coordinator and the international steering group. Guidelines and a collection of complimentary qualitative methodologies are currently being developed.
- Each national partnership should ensure that the research done with the *People Living with HIV Stigma Index* is implemented and linked with other studies of stigma and discrimination relating to HIV in the country context.
- The national partnership should seek to maintain a gender balance in terms of women and men living with HIV involved in the project at the level of leadership, capacity building, and data collection. Referrals, follow up or support should be gender sensitive. Any problems with meeting either of these standards should be communicated to the international coordinator of the index

3) ETHICAL REVIEW

The People Living with HIV Stigma Index, like other studies that collect data from people, must observe certain standards with regard to ethical issues and data protection.

- In each country where this survey is carried out, those responsible for conducting the study should make sure that it conforms to that country's ethical and data protection requirements (see part 3 of the User Guide regarding ethical issues). Two issues are of particular importance:
 - 1) Informed consent: The principle of informed consent means that each interviewee must be asked to consent to the collection and processing of their personal data after being fully informed about the

nature of the study, who is involved in it, how the data will be processed and stored, and what the data will be used for.

- 2) Confidentiality: Confidentiality is concerned with the issue of who has the right to access data provided by the participants of a research study. When conducting research, one should always ensure that appropriate measures are put in place so as to make absolutely certain that the information participants have disclosed and their identity are kept in confidence.
- In each country, the national partnerships should ensure that participation is open to all people living with HIV from a variety of different organisations and networks. Mechanisms should be put in place to protect the confidentiality of all individuals involved in the implementation of the Index, not only of interviewees.
 - Transparency of the coordination of the national rollout and accountability to all stakeholders (national and international) is essential.

4) COMMUNICATION

- The questionnaire should be translated into local languages as appropriate
 - For country-to-country comparison the questionnaire should be the same regardless of the language it is in. The translation therefore needs to ensure that the meaning of each question remains the same as the original English.
 - Each translation should be checked for accuracy and sensitivity to ensure that the questions retain the same meaning as the English original
 - Each translation should be reviewed by at least one person living with HIV
- Where possible, country teams should share reflections and best practice with each other
- Any publications resulting from *The People Living with HIV Stigma Index* should include the logo; be communicated to appropriate national and international partners (before and after finalization); and should be listed on the website www.stigmaindex.org

5) BUDGETING AND RESOURCE ALLOCATION

- At least 50% of each budget should be spent on the capacity building of networks of people living with HIV and of the people living with HIV who will be involved in the research team
- Each budget should include a budget line for advocacy and communication

6) RELATIONSHIP WITH THE INTERNATIONAL INITIATIVE

- Consistent communication and reporting should be maintained with the international coordinator of the index to ensure consistency with other country initiatives.
- Technical assistance can be provided by the international coordinator of the index on behalf of the international steering group. Technical assistance can also be sought from the regional partners—the UNAIDS regional Support Teams, the Regional networks of people living with HIV, and the Regional Office for IPPF
- All ideas and suggested additions for the questionnaire should be discussed with the international coordinator; and approved by the international coordinator in consultation with the international steering group
- All ideas and suggested qualitative methodologies to compliment the work with the index should be discussed with the international coordinator; and approved by the international coordinator in consultation with the international steering group.

7) INTENDED USE

The People Living with HIV Stigma Index is intended for use as an empowering research tool for developing evidence based advocacy by and for people living with HIV. The Index has been developed through extensive field testing in pilot studies and when implemented in its entirety (as outlined in the User Guide) has shown to be a valid and reliable tool. It is not intended for any other use.

