

**CHOOSING RIGHTS: THE PUZZLE OF THE RIGHTS FRAME IN HIV
ACTIVISM**

by

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Abstract

HIV activists are at the vanguard of a critical point of expansion in the use of human rights discourse in advocacy, marking a site of civil society innovation. Drawing frequently and emphatically on rights in place of more traditional frames of development or public health, civil society groups working on HIV provide valuable insight into how and why the language of rights is being adopted in new *fora*. This dissertation examines why civil society groups conducting advocacy on HIV in sub-Saharan Africa, the region of the world hardest hit by the pandemic, choose to (or choose not to) employ the language of rights in their advocacy.

Using a comparative case-study approach, this study examines nine civil society organisations conducting advocacy on HIV. Organisations were selected from countries (Ghana, Uganda, Botswana, South Africa) in the three regions of sub-Saharan Africa (West Africa, East Africa, Southern Africa). Within these countries, civil society groups were identified with variation in regards to their use or non-use of the rights frame. A total of 145 semi-structured interviews were conducted within these organisations, as well as with other organisations in the HIV sector, international organisations, and government officials. Data from interviews was triangulated with information from naturalistic observation, analysis of organisational materials, and laws and press accounts.

These case studies highlight the roles and beliefs of individuals, as leaders, advocates and recipients. Organisational adoption of rights is heavily influenced by leadership, and by secretariat-based organisational structures which allow for a high level of interaction with leaders. Within these groups, a strong personal belief in the rights frame is common. The chief motivation for rights use in advocacy within these organisations is rooted in a belief

that the rights frame has a profound impact on the identity and behaviour of the group's constituents. Proponents understand rights as an empowering force enabling their target group to better seek and access health care services and to do so from a position of strength and entitlement. In contrast, in groups with limited or no rights use, need-based claims highlighting vulnerability were dominant.

Preface

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List of Acronyms and Abbreviations

AIDS: Acquired Immunodeficiency Syndrome

ARASA: AIDS and Rights Alliance for Southern Africa

ARVs: Anti-Retrovirals

AU: African Union

CHRAJ: Commission for Human Rights and Administrative Justice (Ghana)

BONELA: Botswana Network on Ethics, Law and HIV/AIDS

DFID: Department for International Development (UK)

HIV: Human Immunodeficiency Virus

ICCPR: International Covenant on Civil and Political Rights

ICESCR: International Covenant on Economic, Social and Cultural Rights

ICW: International Community of Women Living with HIV/AIDS

Kuru: Kuru Family of Organisations

NACWOLA: National Community of Women Living with HIV/AIDS

NAP+: National Association of People Living with HIV/AIDS Ghana

OAU: Organisation for African Unity

OVC: Orphans and Vulnerable Children

PATAM: Pan-African Treatment Access Movement

PEPFAR: President's Emergency Fund for AIDS Relief

PMTCT: Prevention of Mother to Child Transmission

SADC: Southern African Development Community

SIDA: Swedish Institute for Development Cooperation

SWAA - Ghana: Society of Women and AIDS Ghana

TAC: Treatment Action Campaign

TASO: The AIDS Support Organisation

UDHR: Universal Declaration of Human Rights

UN: United Nations

UNAIDS: United Nations Joint Program on AIDS

UNHCHR: United Nations High Commission on Human Rights

UNDP: United Nations Development Program

USAID: United States Agency for International Development

WAJU: Women and Juvenile Unit (Ghana Police)

WHO: World Health Organisation

WUAAG: Women United Against AIDS in Ghana

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Chapter 1: Introduction

HIV/AIDS is usually, and accurately, depicted as a virus of devastation, leaving children without parents and robbing countries of workers in their prime. In the midst of this devastation, however, the virus is leaving another, very different legacy. In the face of the pandemic, civil society has rallied in new and unexpected ways, identifying resilience and illustrating its response to the pandemic as a site of innovation. Where health activists have traditionally grounded their claims in the language of development or public health, HIV activists often frame their claims in the language of human rights. Groups working on HIV are the early innovators of the expansion of rights-based advocacy into health, a linguistic transition that continues to occur and spread into other health topics, particularly those related to women and reproductive health. While this shift in language is easily observed, it is little understood. Why is it that groups have chosen to use the frame of human rights for issues that could more easily be conceived of in other frames, including those of development, human security and human capabilities? What are the factors driving this choice?

Rights-based health advocates are relatively new actors who have not historically been understood as human rights activists and who are mobilising on topics that have not traditionally been addressed as human rights. These actors are muddying the waters between civil and political rights and economic, social and cultural rights as well as between the concepts of active and passive rights violations. As such, these rights-based health advocates hold the potential to increase our knowledge about how and why frames are adopted into new topic areas, how rights-based health advocacy may differ from activism on civil and political rights, and what the impact of rights-based advocacy on health is for people on the ground. Rights-based health advocacy is

located at the juncture of several important fields of inquiry including the study of human rights, public health and health promotion, civil society, and trans-national advocacy.

1.1 Health and Human Rights: The Puzzle of Frame Choice

The HIV pandemic heralded the birth of the contemporary field of health and human rights, two concepts which continue to have a complex interaction. Both are essential components of human existence, with the first often understood as a professional, scientific, systematised endeavour with a broad consensus on the value of its objectives, whether it is understood at an individual or population level. Although definitions and understandings of health vary, the value of health is usually a goal that government and civil society agree upon. Arguments based on health call upon the shared basic physical needs of human beings to survive and thrive, allowing health to sometimes be used as a trump card over political, military, security or trade issues. Examples of the humanitarian side of this dynamic are visible in activities such as humanitarian ceasefires for vaccinations, while the field of international public health emerged from the restrictive side of the same coin in the form of quarantine regulations. The health frame is not one which depends on a structure of blame. It can, much like a natural disaster, be framed as a harming of innocents – where there is no violator, no responsible party. These characteristics make health an enviable frame for those swimming in more contested waters. And yet, while a diverse grouping of advocates on environmental, security, political, humanitarian and military issues are, in some respects, clamouring to use the health discourse for such reasons, there is also increasing traffic in the other direction. Those who are securely grounded in health issues are simultaneously making their way towards the politics and polemics of the rights frame. Why they might do so, particularly when others see the health frame as advantageous, is the central puzzle of this research.

In contrast with health, human rights are understood as overtly political. The rights frame is one that requires and is constructed around blame. Human rights are conceived of as violations with victims on the one side and violators on the other. It is a divisive and politicising discourse that is both a rallying call, and a pointing of the finger. With rights claims, this accusatory finger is, in most instances, directed squarely at the state as it is identified as the primary duty-bearer.¹ Yet despite the risks of political division, and calls of cultural imperialism or local inappropriateness, the rights frame is increasing in popularity among civil society groups campaigning on health issues. Health and human rights have been linked together in advocacy in two distinct ways. The first, often using the phrase ‘right to health,’ has emphasised population or collective health and has targeted structural factors inhibiting the construction of functional health systems. The second, sometimes described as ‘health and human rights,’ has grown from experiences of inequity and rights violations at local and global levels. Campaigns in this second category, health and human rights, have occurred in circumstances that might be described as a combination of most and least likely cases. They are examples of the most expected courses of action because the earliest calls have been to one of the most basic, and universally documented, human rights – that of non-discrimination. Initial campaigns have centred on discrepancies in access to treatment and impact on lifespan, or variation in medical care or cultural practices in different parts of the world, and the resulting health impacts. What is perhaps less expected is that the cases where the rights frame has been employed most emphatically are areas relating to stigmatised and taboo groups and practices. The frame has been applied to issues that are already significantly politicised, and divide or stand to divide societies. The rights frame has most often

¹ There are some exceptions, in the health sector pharmaceutical companies and the international community are also identified as duty-bearers in some instances.

been used in cases where there is some societal perception of blame, unease, disgust or taboo with respect to either the person, the mode of transmission or the practice being campaigned on. These are cases where one might expect a trend towards attempted de-escalation or de-politicisation rather than the reverse.

HIV is the vanguard case of extensive global health campaigning using the rights frame, primarily for access to treatment and non-discrimination. Overt public discussion of sex is taboo in most cultures, and, in addition, in some societies the disease has disproportionately targeted groups that are further stigmatised including men who have sex with men, sex workers, injection drug users, people who live on the street, and prisoners. In other societies HIV is a generalised² epidemic that has created stigmatised groups: i.e., those living with, or living openly with the virus, those having children while known to be positive, etc. Those campaigning against female genital cutting and for women's reproductive health rights have also adopted the rights frame, although these campaigns are less widespread and less systematic in their use of rights language.

What has spurred this wave of boundary crossing? On a global scale observers have theorised that the initial manner in which HIV emerged and was addressed in Europe and North America may have laid the groundwork for the utilisation of human rights in this context. Early outbreaks in these settings were linked to marginalised groups, such as Haitian refugees and gay men, and to behaviours considered to be taboo or disreputable such as sex between men, promiscuity and

² A generalised epidemic exists where prevalence rates are higher than 5% and are not concentrated among a specific population group (for example, if an epidemic is concentrated among sex workers but there are very low rates in the broader population it would be considered a concentrated rather than a generalised epidemic). Areas with rates higher than 15% are sometimes additionally classified as hyperendemic. For further information on epidemic classification, see: UNAIDS HIV Prevention Toolkit, "What are the Different Epidemiological Scenarios." http://hivpreventiontoolkit.unaids.org/support_pages/faq_diff_epi_scenarios.aspx (Accessed 27 September 2012).

sex work (Mann 1999, 217-218). Initial public health responses featured scare tactics directly equating the virus and those infected with it with death. Indeed, far from using rights to support those infected, initially it was argued that, in the face of such a horrific public health emergency, rights could, indeed should, be compromised (for a discussion of this argument see: Mann 1999, 216-226; Mann and Tarantola 1998, 5-8). These strong statements provoked a counter-response emphasising rights in the face of discrimination and stigma.

After the discovery and introduction of anti-retroviral drugs (ARVs), the conversation around HIV and rights took on new dimensions. In at least some cases, ARVs allowed for HIV to be transformed from an imminent death sentence to a manageable chronic condition. ARVs, however, were neither uniformly available nor equally affordable across countries or populations. The inequity in access to medication and the resulting impact on lifespan were highlighted by activists as abuses of human rights, whereby those who could access drugs lived, and those who could not died. Finally, Davies argues that rights also became a popular language of mobilisation and funding and one through which it was easier to attain buy-in from key stakeholders (Davies 2010).

These broad stroke explanations, however, have tended to be based at the macro-scale, identifying possible contributing factors to an emerging discourse based in the global north and west during the 1990s. Decisions, however, are not made in broad settings, but by individuals in particular times and circumstances, and not all activists have adopted a turn to rights. This study aims to understand the choice to use rights at an organisational level examining civil society groups working on HIV advocacy on a continent where the virus has predominantly been a

generalised rather than concentrated epidemic, and where rights are not usually a common approach.

1.2 HIV in Sub-Saharan Africa

Sub-Saharan Africa's HIV pandemic provides an ideal and challenging context for an exploration of the use of rights advocacy. Nowhere has the pandemic hit as hard as it has in Sub-Saharan Africa. While the region has a mere ten percent of the world population it accounts for 68% of the world's people living with HIV, and 75% of the deaths (UNAIDS 2010). More than 22 million people in Sub-Saharan Africa are living with the virus (UNAIDS 2010). It has reversed development progress, in some cases reducing life expectancy by up to 20 years in heavily affected countries (for example Botswana and Swaziland).

If an 'easy case' through which to examine the research question is a region with common cultural and linguistic traits, where there is the economic ability to provide care through a public health system and where the concept of human rights has a long history, then Sub-Saharan Africa is zero for three. Home to more than 900 million people, in more than 50 countries, Sub-Saharan Africa is a region with enormous variation in language, religion (including Islam and Christianity as well as countless local belief systems), politics, geography and population density. The region's 24.3 million square kilometres is the world's poorest, and the only region to have seen an increase in absolute poverty between 1981 and 2001 (BBC 2004). Efforts to alter this trajectory, such as overseas development assistance and the Millennium Development Goals have been challenged among other things, by the economic impact of malaria and HIV and, most recently, by the consequences of the global economic crisis which is estimated to result in a 60 percent decline in projected GDP growth (World Bank 2008). Hard hit by

structural adjustment programs, out-migration, and the HIV pandemic, health services have disproportionately felt the economic crunch in many countries.

While human rights have long-standing roots in Europe and North America, their identification and importance is still uncertain and contested in Africa. Some argue that they are imported ideas inconsistent with communal “African values,” while others contend that they reflect local concepts of a reciprocal recognition of human-ness (see: Cobbah 1987, 309-331). The African Union (AU) reflects a mix of these ideas, codifying human rights standards while highlighting certain local features, including an emphasis on collective rights (ie the African Charter on Human and People’s Rights), the mention of “duties” unlike other regional and UN documents, and calls for the discontinuation of harmful cultural practices (Organisation of African Unity 1986). The idea of confrontationally being held to a standard originating from outside of the state is also controversial within Africa. This is reflected in everything from Robert Mugabe’s persistent denunciation of what he perceives as colonial meddling in Zimbabwe by the UK, to Botswana’s outrage at the involvement of the NGO Survival International in what they saw as the domestic matter of the relocation of indigenous peoples, to Thabo Mbeki’s long reluctance to acknowledge a link between HIV and AIDS in South Africa. A non-confrontational approach, an approach that is dominant in the African context, is reflected in the AU’s unique peer review enforcement mechanism and a series of processes that emphasise carrots over sticks, and engagement and relationship building over punishment and isolation. In summary, this project aims to investigate the framing of an unprecedented health pandemic as a rights issue, in a context where that frame would not be expected to emerge or succeed.

1.3 Explaining the Puzzle of the Rights Frame

When choosing whether and when to frame their claims as rights civil society organisations conducting HIV advocacy in sub-Saharan Africa face three areas of possible influence. First, their choice of frame may be influenced by internal organisational factors including history, structure, personnel and perspective of human rights. Second, such groups may be influenced by external factors of context and connection, including whether and how other civil society groups employ rights, what frame government employs, what frames donors prefer and, what local, national and regional coalitions and networks organisations belong to. Finally, advocacy groups formulate their message with the hope of creating change and making an impact. Therefore, organisations may choose their frames based on evidence or expectation of success in influencing government to change law or policy, in mobilising groups of people to act collectively, or in influencing individual behaviour.

Although rights use in health advocacy is a new and relatively unexplored area, literature in related fields such as framing propose several possible explanations within the areas of influence outlined above. The literature suggests that frame choice may be based on personal belief (Hopgood 2006), influenced by resonance with domestic norms and values (Sundstrom 2006) and supported through international linkages (Bob 2007). Frame choice could also be shaped by donor preferences (see, for example Kindornay, Ron and Carpenter 2012), or by instrumental or strategic expectations of impact. In short, we might expect to see rights-based groups led by people who believe in rights, located in rights-based settings, supported by rights-favouring donors. These groups likely explain their use of this frame based on the expectation that it will lead to changes in law, government policy or behaviour (Forman 2008, Gloppen 2008).

To preview my argument briefly, I argue that organisations choose rights due to a combination of principled and structural factors. The ideal set of conditions for organisations to choose rights as a dominant frame includes components relating to leadership, organisational structure and expected impact. Organisations employing rights as a primary frame have strong leaders with a clear rights orientation whose ability to develop a rights-based organisational culture is mediated by organisational structure. These leaders choose rights based on a strong principled belief in rights spurred by personal experience, study, and, in some cases, witnessing of the frame's impact. In settings where rights are not a dominant domestic discourse a centralised secretariat-based structure allows for regular interaction with leadership and the development of a strong internal and external identity as a rights oriented group in a setting of relative isolation from a broader rights-based discourse. Where rights are a common local language of advocacy, the use of rights language can be supported by domestic discourse and more decentralised membership-based structures. Perceptions of impact are the primary motivating factor for organisations to select rights. They choose rights as a dominant frame primarily because they expect that it will alter how individuals interact with health care providers enabling them to claim services from a position of entitlement and strength.

This argument differs from the existing literature in several important ways. First, resonance of the rights frame at an individual level appears to be central, rather than resonance with domestic discourse. Second, rights dominant groups can and do exist in domestic settings where rights are not a common language of advocacy. Third, although funding is very important, rights-oriented donors do not appear as critical influences in the decision of organisations to adopt or maintain a

rights dominant frame as a political economy explanation would expect. Fourth, the most important impact of rights is understood as individual, rather than linked to legal accountability, policy change, government response or public mobilisation.

1.4 Overview of Structure

This dissertation unfolds in three parts. The first third, which includes chapters 2 and 3 introduces the theoretical and methodological structure of the argument. Chapter 2 serves to situate the research with reference to key concepts and to identify possible hypotheses in the literature to be explored in the empirical chapters. Chapter 3 outlines the methodological framework and its operationalisation. The second third, which consists of chapters 4, 5 and 6 presents the empirical data from the nine organisations studied. Chapter 4 examines three organisations which hold a rights dominant approach. Chapter 5 analyses three groups which use a rights approach in concert with other frames. Chapter 6 examines three organisations which make limited, peripheral or no use of rights in their advocacy. The final third, which consists of chapters 7 and 8 examines and discusses the findings from the empirical chapters. Chapter 7 conducts a comparative analysis of the nine cases studied while Chapter 8 distills the overall findings and suggests areas for future research.

Chapter 2: Theoretical Framework

The use of rights-based advocacy by civil society groups working on HIV in sub-Saharan Africa is a complex phenomenon drawing together personal belief, human rights in local and international contexts, multiple dimensions of health and civil society, and the concept of framing. It is a process that can be intensely personal and locally grounded, but also one that maps a journey of ideas between and across sectors and continents, tracing routes of infection, flows of funding, and networks of collaboration. African HIV activists draw upon these beliefs, experiences and interactions to create an unexpected form of advocacy.

This chapter aims to situate the research question - “Why do civil society organisations conducting advocacy on HIV in sub-Saharan Africa choose to express their claims in the language of rights” - in relation to the literature. This is done with two objectives addressed in sequence. First, this study seeks to contribute to understanding a real world phenomenon of disciplinary boundary crossing. It examines human rights being pulled into the sphere of HIV and health by civil society actors through the process of framing. As such, this chapter begins by locating the research question in relation to these four key topics: human rights, health, civil society and framing. An exploration of these factors also serves to highlight the puzzle of rights choosing in the HIV sector in sub-Saharan Africa, indicating why such a development is new and unanticipated. Second, this chapter identifies possible answers to the research question by identifying hypotheses from relevant areas of literature as well as those that emerged from the field. The final section of this chapter previews the structure of the comparative analysis of the case studies.

This dissertation puts forward an explanation that organisations choose to frame their claims as rights primarily due to a firm belief in the individual-level impact of rights, which is transmitted through strong leadership and facilitated or constrained by organisational structure. Where rights are not locally dominant, centralised secretariat-based organisational structures serve as incubators for a rights-oriented organisational culture. Where rights are locally prominent, a rights orientation can be reinforced by domestic factors and organisations may have a more membership-based decentralised structure. This explanation is significant both for what it includes and what it does not. These findings are surprising in that they do not indicate that donor orientation is critical in the selection of the rights frame. Neither do they show high-profile outcomes such as legal accountability, policy change, government response, or public mobilisation as key motivating factors in frame selection. While some of these factors may provide answers to a more general question (why do organisations choose the frames they do?) several features of rights and rights-choosing are unique, and specific to this frame. The central role of belief and the perception of strong individual-level impact are features of the choice and use of the rights frame that do not appear to have straightforward parallels among other frames such as health or development.

2.1 Key Concepts: Human Rights, Health, Civil Society and Framing

Health advocacy has traditionally been understood and communicated using frames of development and public health. Departing from this tradition, many HIV activists have adopted a rights-based frame in advocacy. This frame is being employed internationally even in settings where rights are unfamiliar, where advocacy norms favour consensus, and where civil society may have closer links to and more direct interaction with the state. The reasons for the use of

rights in these settings are a puzzle, as are the ways in which rights are understood, wielded and perceived to act.

This project is premised on the idea that the use of rights language, understood as direct references to rights, is a choice rather than an inevitability. This project assumes that reference to rights is not a necessity and that other linguistic frames exist that could likely alone or in concert be utilised for similar objectives. The question being examined here is why groups that have a variety of discourses at their disposal choose to refer to rights in their campaigns, acknowledging that arguments based on development, public health, human security, poverty or stigma are also possible. Thus the question is not how a rights-based discourse is inherently different from other frames, but why and how groups choose to use rights.

Rights-based advocacy on HIV is a phenomenon that exists at the intersection of several practical sectors and fields of research. It is a practice that emerges from civil society using framing to draw on human rights in the context of HIV. As such, this research question necessarily explores the spaces between fields and examines points of convergence and overlap among them. As Nelson and Dorsey argue:

We have become convinced that conventional approaches to human rights, non-governmental organisations, and development – their visions shaped by disciplinary and professional boundaries – are missing important changes that are most evident at the disciplinary boundaries and the organisational interstices (Nelson and Dorsey 2008, 6).

This research question draws on literature and engages with debates in four existing areas of study: human rights, health, civil society and framing. Consequently it is necessary to situate the research question in relation to each of these fields. This section explores these fields of research briefly with emphasis on the evolving boundaries within and between them.

While human rights, health and civil society have each had a recent heyday³ including a high level of attention among academics and practitioners, the interaction and overlap between all three topics, while extensive on the ground, has been limited in the literature. Each of these key words- human rights, health, and civil society - can be understood in multiple ways. They can be viewed as ideas, concepts or frames, and as measurable realities in the form of actors (i.e., number of registered NGOs) or outcomes (changes in law or decreased disease prevalence). Human rights are seen as a rhetorical frame, a legal instrument, a state record of good treatment of its citizens, the existence of legal recourse, an aspirational ideal, or a philosophical construct. Health can and is conceived of as the absence of illness, the existence of a health care system, an approach or frame, the preconditions for good health, or positive health outcomes. Civil society can be understood as an outcome or cause of a democratic and/or rights-respective system, as an arena or an actor. This theoretical overview, in line with the research question, examines these concepts in a particular context. In examining why civil society groups employ rights in HIV advocacy, I view human rights as a tool, utilised in the arena of health by civil society actors.⁴ Framing is the manner in which civil society employs this tool.

2.1.1 Human Rights

The question of why civil society groups working on HIV in sub-Saharan Africa use human rights in their advocacy is one that contrasts with several common practices and divisions in

³ The modern conception of human rights has become a central concept in the post war period, with recent peaks of prominence in the late 1990s and current day. Public health has been a relative constant, with spikes in global presence as an area of attention relating primarily to emerging infectious diseases, including HIV/AIDS, but also more recently to Severe Acute Respiratory Syndrome (SARS), H1N1 and Avian Flu. Civil society surged to the forefront in the 1990s and continues to hold significant importance in discourse and in the practice of international development and relations.

⁴ Separating concepts that are linked and interpreted in multiple ways is always a bit dangerous and involves a slight fiction. This is particularly the case with reference to health and human rights, as many actors see one concept as a subset of the other. Thus whether advocacy on rights that relate to health is the use of human rights in the sphere of health, or the use of rights in the sphere of rights, is debated with some seeing health as the larger whole encompassing rights, and other seeing rights as the larger whole encompassing health.

human rights research, codification and use. First, human rights are usually understood as a legal tool with emphasis placed on codification in domestic and international law and state compliance. Second, as a general term, human rights has at least in the global north been predominantly associated with civil and political rather than economic, social and cultural rights. In the field this has been reflected in a division between the human rights sector which emphasises civil and political rights and the development sector which addresses economic, social and cultural rights including health. Third, the geographic universality of rights is frequently questioned with rights depicted as a western or northern construct.

2.1.1.1 Human Rights as a State-Oriented Legal Tool

The current vision of human rights is intimately connected with the United Nations systems and its mechanisms of codification. The 1948 Universal Declaration of Human Rights (UDHR), recognised that “all human being are born free and equal in dignity and rights” (Article 1) noting that “recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world” (preamble). Despite, or perhaps because of their now extensive codification, rights are understood in diverse ways. Viewed as simultaneously essential and aspirational, the “chameleon-like term” can refer to an entitlement, an immunity, a privilege, a power (Shestack 1998, 203), access, a desire, as well as a rectitude (“the right thing to do”) (Donnelly 2003, 7). As Donnelly argues, the meaning of rectitude and entitlement both “link ‘right’ and obligation” with the former highlighting a standard of conduct, and the latter emphasising the right-holder’s claim on a right in relation to the duty bearer (Donnelly 2003, 7).

The broad objectives of human rights are codified in more detail in a series of legally-binding human rights treaties, most notably the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR). These documents present rights in particular ways. Rights are affirmed and defined through their inclusion in these covenants with the process of drafting being an elite process and the outcome a legalistic rather than popular document. Although not exclusively defined as such, the human rights legal system has been primarily conceived of as mediating a relationship between the individual and the state within which that individual resides, with the former the rights-holder, and the latter the duty-bearer. As such, covenants are directed at states and signed and ratified by them. Covenants are also relatively static, remaining as initially written, with only the possibility of reinterpretation by the relevant committees, by the addition of general comments or by the development of additional documents such as related additional protocols. Monitoring is a formal process of accountability wherein the state reports on its performance to the relevant committee, with some allowance for input by civil society groups in the form of a shadow report.

This legal emphasis is not without critique. As Freeman notes:

Worldwide the understanding and practice of human rights are strongly dominated by legal thinking, practices and institutions. However, in recent years there has been a growing recognition that this dominance has been excessive, and has inhibited both our knowledge of what human rights are and how they can most effectively be realised (Freeman 2012, 13).

Hastrup is also critical of the idea of a rights culture emerging from legal creations, describing it as “a peculiar culture in the sense that it is declared rather than lived” (Hastrup 2003, 16-17).

Pulling the concept of human rights from law into lived experience, a number of scholars examine the role of non-state actors such as civil society groups on the enforcement and enjoyment of human rights (Nelson and Dorsey 2008, Keck and Sikkink 1998, Risse, Ropp and Sikkink 1999, Risse Ropp and Sikkink 2013, Simmons 2009, Wong 2012). Risse, Ropp and Sikkink, for example, posit a ‘spiral model’ of interaction between international and domestic civil society and government in pursuit of the domestication of civil and political international human rights norms (Risse, Ropp and Sikkink 1999, see also Risse, Ropp and Sikkink 2013). In this model, the main stumbling block to the domestic recognition of rights is legal legitimacy and domestic civil society links to international groups in order to shame and presume the government to adopt the language and practice of human rights. Keck and Sikkink similarly examine the process of mobilisation and influence advocating a “boomerang effect” whereby domestic civil society groups encountering repression or indifference liaise with international civil society allies who, in turn, lobby their own governments to put pressure on the target state (Keck and Sikkink 1998). Simmons describes the importance of the vigilance and pressure of domestic civil society in pushing for ratification, and in linking ratification to compliance (Simmons 2009). While these models open the sphere to include non-state actors using rights as a language of advocacy, they remain state-centred in that the objective is to influence government behaviour with the goal of changing laws and enforcing them. The idea that rights may be used with the end goal of influencing behaviour by an actor other than the state is little explored.⁵

⁵Alison Brysk’s chapter “Changing Hearts and Minds: Sexual Politics and Human Rights” in: *The Persistent Power of Human Rights: From Commitment to Compliance* is one recent example of an exception to this rule (see: Brysk, Alison. 2013. “Changing Hearts and Minds: Sexual Politics and Human Rights.” *The Persistent Power of Human Rights: From Commitment to Compliance*, eds Thomas Risse, Stephen C. Ropp and Kathryn Sikkink. Cambridge: Cambridge University Press, 259-274. , eds Thomas Risse, Stephen C. Ropp and Kathryn Sikkink. Cambridge: Cambridge University Press, 259-274.).

2.1.1.2 Generational Divides

HIV activism traverses well-defined boundaries between first (civil and political) and second (economic, social and cultural) generation rights employing rights on issues ranging from workplace discrimination to provision of health care. The International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights illustrate a divide between first and second generation rights with clear differences in wording, perception and application. Sometimes characterised as ‘positive’ and ‘negative’ rights, a perception exists that ‘positive’ rights (requiring action to be undertaken) are more likely to entail substantial state infrastructure investment than ‘negative’ civil and political rights which require the state to refrain from committing violations (ie the absence of a violating action). Gostin and Lazzarini reflect this perspective in their writing, noting that the “emphasis on incremental achievement” in the ICESCR “acknowledges that many of these rights require an ample investment of human and material resources and recognises that states occupy disparate levels of economic, social, educational and infrastructure development” (Gostin and Lazzarini 1997, 7). They state that, in the postwar era when these documents were created, “even the most rudimentary state-supported health institutions and programs were often unavailable outside of major cities” in the developing world (Gostin and Lazzarini 1997, 7). Consequently, they conclude that to have expected such countries to fulfill ICESCR rights “quickly would have been unrealistic,” commenting that “[e]ven now, some countries might never achieve these steps without international assistance” (Gostin and Lazzarini 1997, 7).

The positive/negative distinction, however, is not accepted in all quarters (Shue 1996, Hurrell 1999, 280, Ashford 2009, 92-112). A stark dichotomisation is, at least in part, inaccurate. As former Special Rapporteur on the Right to Health Paul Hunt noted, “an effective health system is a core social institution, no less than a court system or political system” (Hunt 2006, 1-22) and rights such as a fair trial require initiatives involving financial outlay such as the development of a legal system and related infrastructure. Questioning this dichotomisation, Holmes and Sunstein argue that “all rights are positive” noting rights rely on remedies which involve cost for their enjoyment, and that “rights are costly because remedies are costly” (Holmes and Sunstein 1999, 43). Instead of attempting to locate all rights as “positive,” Landman disaggregates each right, locating “*positive and negative dimensions*” within each one defined as the “provision of resources and outcomes of policies” (positive) and “practices that deliberately violate” (negative) respectively (Landman 2006, 10-11). The right to health, for example, consists of state investment in infrastructure and services, and non-discrimination in access with respect to “ethnic, racial, gender or linguistic” factors (Landman 2006, 11).

Reflecting the 1993 Vienna Declaration, which, in response to many of the critiques noted earlier, trumpeted that “[a]ll human rights are universal, indivisible and interdependent and interrelated” there are those who challenge the idea of classifying rights into ‘generations’ at all arguing that such a division is “crude and easily (mis) read to suggest that the two categories are antithetical” (Donnelly 2003, 27-28). Arguments in this vein posit that “it is impossible to talk about certain sets of human rights in isolation, since the protection of one right may be highly contingent on the protection of other rights,” noting that the right to vote is “largely meaningless” without “adequate health, education, and social welfare provision” (Landman 2006, 10). Mirroring the positive/negative split, Donnelly argues that the generational divide has

roots, primarily through the earlier work of Maurice Cranston, in the valuing and legitimating of civil and political rights over social and economic rights (Donnelly 2003, 28-29).

2.1.1.3 Universality

Despite the claims of the Vienna Declaration, the universality of human rights and human rights goals are often called into question for both cultural and strategic reasons. Although not as prominent as the Asian values debate which came to a head in the mid 1990s, in the African context rights are sometimes seen as a northern or western import inappropriate to local norms, beliefs and circumstances. One of the chief arguments held up to indicate the foreignness of rights in Africa, is that rights emphasise the individual, whereas African cultures highlight community. While some have used this argument to indicate the unsuitability of rights discourse in Africa, others have examined how a sociocentric perspective contributes to African conceptions of human rights. As Cobbah argues, the point of departure is the question “what is the basic unit of society?” noting that “an African philosopher may answer that it is the extended family” (Cobbah 1987, 318-319). Cobbah argues that in the African context a “more solid foundation for modern human rights can be built on a conception of man in society rather than the Lockean abstraction of natural rights” (Cobbah 1987, 318). He notes that, “[a]s a people, Africans emphasise groupness, sameness, and commonality” (Cobbah 1987, 320). In an African context “freedom was belonging rather than autonomy” (Englund 2004, 17) with “African thought stress[ing] ... the right of the individual to become part of the group” (Howard 1980, 731). While some posit that arguments emphasising communality call upon an idealised (and no longer existent past) (Howard 1986), others see these concepts as “remarkabl[y] resilient” to more individualized conceptions of human rights (Nyamjoh 2004, 36). At the highest level, there are arguments over whether it is possible to have regional or culturally-located conceptions of

human rights, or if such variation more accurately reflects differing perceptions of human dignity (Donnelly 1982, 303-316, Howard 1986, Donnelly 1984, 400-419, Cerna 1994, 740-757). In the African context this debate, as Hawkins argues includes both “Afropessimism” where “African values [are seen] as inimical to the realisation of ... rights” by international definitions and “Afrocentric critiques that deny the relevance of human rights by dismissing them as but another instrument of neo-imperialism” (Hawkins 2007, 394-395).

Rights as depicted here, as a legal state-oriented tool cleaved by generational divides and with contested universality, highlight the unexpected nature of HIV advocacy. African HIV activists frequently use rights outside of the legal realm, mix the two generations of rights and employ rights in a region where rights are sometimes contested as foreign impositions. In contrast with the three features explored, the research question also illuminates important gaps in research and thinking about the use and purpose of rights as an advocacy tool. In particular it suggests the need for greater understanding of non-state directed human rights advocacy and exploration of the nature of rights-based advocacy in the African context.

In addition to culturally-based conceptual objections, universality is also questioned as a strategic choice. Hafner-Burton argues that in pursuing improved human rights globally it is important to move away from universal goals with global application (Hafner-Burton 2013). Instead, she argues, more attention needs to be paid to the specific and unique roles of specific states, the setting of priorities, and the identification of realistic outcomes in particular settings (Hafner-Burton 2013).

2.1.2 Health

As discussed above, rights-based HIV advocates engage with human rights in unconventional ways in an unexpected setting. So too do these activists interact with health in unique ways that present a departure from past health advocacy. By choosing to frame their claims as rights rather than development or public health goals, HIV activists are breaking new ground. This section explores the sources and origins of this linguistic innovation by tracing contemporary linkages between health and human rights. This is examined in three parts: first, exploring the emergence of human rights discourse on HIV internationally, second analysing the growing health and human rights field, and third exploring the related public health construct of social determinants of health. While this background provides useful context and indicates the possible intellectual heritage of rights-based advocacy on HIV, it is not a discourse that originates from, responds to or directly engages with the African context. It is also not a conversation that places civil society at the centre. Thus, the question of why sub-Saharan civil society groups working on HIV employ rights attempts to understand the phenomenon of rights-choosing in a specific context and by a specific set of actors aiming to trace linkages between the local and international.

2.1.2.1 HIV

Contemporary health and human rights discourse is intimately linked with the HIV pandemic (Gruskin, Mills, and Tarantola 2007, 449-459). This linkage was facilitated by the manner in which the virus was initially addressed in prevention campaigns, the emphasis on social context and groups as vectors or vulnerable (or both), and the global disparity in access to medicine once anti-retrovirals became available.

Globally, most early prevention campaigns focused on scare tactics, “emphasis[ing] ‘danger’” (Mann and Tarantola 1998, 5) and “s[eeing] to inform and often, explicitly, frighten” (Mann

1999, 216-226). The messages often included images of skulls and the grim reaper, equating the virus with death (Morlet, Diefenthaler, and Gold 1988, 282-286, and Australian Broadcasting Corporation 2007). While understandable in a context of fear and in the absence of treatment, these prevention-oriented campaigns fueled stigma and discrimination against those already living with the virus (U.S. Centers for Disease Control 2002). Dividing early responses to HIV into three periods, Mann notes that following the period described above (1981-1984), there was a focus on individual risk reduction, which included recognition by the WHO of non-discrimination against those living with HIV as a key component of effective public health (1985-88), and from 1988 a more socially-oriented approach to HIV, after which Mann proposed (and foresaw) a subsequent emphasis on human rights (Mann 1999, 217-218). The human rights approach emerged from a non-discrimination perspective and included arguments around access to care, but also an emphasis on confidentiality regarding medical records, and, in particular HIV test results. HIV continues to have one of the most developed and elaborate protocols in this area, emphasising confidentiality and informed consent. This approach is heralded by some for protecting patient rights, and critiqued by others for contributing to HIV stigma by treating the virus differently than other health conditions (Macklin 2005, 27 - 30; De Cock 2005, 31-32).

Social context was foregrounded early on in the pandemic linking the virus, sometimes incorrectly, with specific, usually marginalised groups, initially gay men and Haitians in the United States (Farmer 2006) and later including stigmatised behaviours such as sex work (PANOS Institute 1990), promiscuity and injection drug use. These linkages exacerbated discrimination in a context of ignorance and fear about the virus (Davies 2010; Maluwa, Aggleton, and Parker 2002, 1-18). A feedback loop developed, whereby, in addition to these existing societal biases, those who were HIV positive also became a marginalised group due to

their sero-status (Maluwa, Aggleton, and Parker 2002, 5). The strength of this response was so unprecedented that Mann referred to the “social, cultural and political reaction” as the “third epidemic,” following the hidden, and subsequently visible viral epidemics, viewing the reaction as being “as central to the global challenge as AIDS itself” (Mann as cited in: PANOS Institute 1990, vi). He later noted that “social marginalisation, discrimination and stigmatisation, in other words a lack of respect for human rights and dignity is itself a root cause of the epidemic” (Mann as interviewed in: O'Connor 1995). Because of the devastating consequences of this discrimination, including refusal of care (Davies 2010), a consequent emphasis on human rights, and non-discrimination arose (Mann 1999, 216-226) even in areas with a generalised epidemic.

Once effective anti-retroviral medications were identified, their high cost and inequitable distribution (being particularly out of reach in high prevalence parts of the world) brought in a new human rights dimensions – equal access to medication, and its direct impact on lifespan across the north-south and rich-poor divides. Health and human rights have continued to be very linked to HIV, with the current UN Special Rapporteur on the Right to Health coming from a background working on HIV. A review of literature over the past decade indicates that while the discourse of health and human rights has expanded, HIV remains the largest area of focus (Mpinga et al. 2011, 1-28).

2.1.2.2 Health and Human Rights: Chronology of the Field

As the close connections to the HIV pandemic indicate, the contemporary health and human rights discourse is a relatively recent invention. More commonly understood within frames of public health or development, as recently as 1999, Mann et al commented that there were “no books focusing on this new field” (Mann et al. 1999, 1). Yet, some interplay between the

concepts of ‘health’ and ‘human rights’ has existed in various contexts for more than a century, including early quarantine restrictions (Center for Disease Control 2007) and later protections for participants in medical research emerging from the post World War II Nuremberg doctors’ trials. With the birth of the UN Human Rights system, the right to health was codified in the UDHR, and further enshrined in several binding human rights conventions including the ICESCR (entered into force 1976). The 1978 International Conference on Primary Health Care, unified the concepts in a more pointed and focused way in the Declaration of Alma-Ata which “strongly reaffirms that health ... is a fundamental human right” (Article 1). While this declaration had an important impact on the form of subsequent health strategies,⁶ it remained largely ignored by the human rights sector.⁷

Despite this history and evidence of codification, it was only with the advent of the HIV/AIDS epidemic in the 1980s that health and human rights merged from “evol[ution] along parallel but distinctly separate tracks” (Gruskin and Tarantola 2005, 3). Crediting HIV and reproductive and sexual health issues for “clarifying the ways in which health and human rights connect” observers have noted that under the leadership of Jonathan Mann in the late 1980s, the World Health Organisation’s (WHO) Global Program on AIDS developed the “first worldwide public-health strategy to explicitly engage with human rights” (Gruskin, Mills, and Tarantola 2007, 449). Interestingly, this strategy emerged primarily for pragmatic reasons, as new evidence

⁶ Its emphasis on equity and primary health care have had a significant impact on the WHO, see for example: Chan 2007.

⁷ This was followed up by the 1986 Ottawa Charter for Health Promotion (First International Conference on Health Promotion 1986) which also emphasised equity but made no explicit mention of rights, and the 1997 Jakarta Declaration on Health Promotion into the 21st Century which openly stated “[h]ealth is a basic human rights and essential for social and economic development’ (Fourth International Conference on Health Promotion 1997).

demonstrated that stigma and discrimination were having a negative impact on the accessing of services (Gruskin, Mills, and Tarantola 2007, 449).

Starting at the outset of the next decade, the UN began hosting a series of international conferences “further solidif[ying] the dual obligations of governments to the health and human rights of their people” (Gruskin, Mills, and Tarantola 2007, 450). Of these, the International Conference on Population and Development (1994) and the Fourth World Conference on Women (1995) proved particularly important. Freedman views the first as “mark[ing] the formal acceptance at the international level of a new paradigm in which health is intimately tied to rights” (Freedman 2005, 532), while the second elucidated these linkages for the first time in “international consensus documents and help[ed] focus attention to the dual obligations of governments regarding both health and human rights” (Gruskin and Tarantola 2005, 4). The 1996 World AIDS Conference held in Vancouver also brought together critical constituencies of scientists and activists, which, in the context of unequal access to new life prolonging anti-retroviral drug cocktails, spurred a human rights perspective on the epidemic among activist communities. In 1997 UN Secretary General Kofi Annan launched the Program for Reform, which gave primacy to human rights as a core UN function, an act that Gruskin, Mills and Tarantola view as an “important step in moving issues of health and human rights from rhetoric, to implementation, action and accountability” (Gruskin, Mills, and Tarantola 2007, 450). By 2001, the United Nations convened a General Assembly Special Session (UNGASS) on HIV/AIDS, resulting in a Declaration of Commitment which clearly linked the pandemic to a human rights frame. The following year the first United Nations Special Rapporteur on the Right to Health was appointed.

The increased linking of health and human rights in various sectors has, however, not been a linear story of progress, nor has it been uncontested. Indeed, Gruskin, Grodin, Annas and Marks note that, “a backlash has developed in high-level policymaking and amongst some public health officials against the integration of rights into health work” (Gruskin et al. 2005, xvii). This is evidenced by the absence of the phrase “human rights” in the Ottawa Charter for Health Promotion (1986), and the reluctance of a number of governments to support a human-rights approach to HIV/AIDS at UNGASS (Gruskin et al. 2005, xvii). This opposition points to the ongoing divide between first generation rights, seen as negative rights, and the perception of second generation rights as positive rights requiring a higher level of government investment. Furthermore, since September 11th, and in the context of SARS, avian flu, H1N1 and other emerging pandemics and biosecurity risks, the old cleavage between public health and human rights has been resurrected, with some “argu[ing] that in times of war and epidemics it is necessary to trade the protection of human rights for health security” (Gruskin et al. 2005, xviii).

Despite these challenges, by 2005, an anthology on health and human rights noted that:

[i]n the last few years human rights have increasingly been at the centre of analysis and action in regard to health and development issues. The level of institutional and state political commitment to health and human rights has, in fact, never been higher (Gruskin and Tarantola 2005, 3).

This historically high level of attention, which includes human rights mainstreaming across UN agencies, articles and special additions addressing human rights and health in health journals (Gruskin and Tarantola 2005, 3) is more an exposition of past gaps than a cause of celebration. The field remains a group of small and disparate niches, an academic diaspora of sorts, acknowledged by experts as being in “its infancy” (Farmer and Gastineau 2005, 77) and full of

calls for additional research.⁸ The field is also one of uneven trespassing across disciplinary boundaries. While linkages between law, public health and medicine are increasing, there is greater movement of public health experts into the social sciences than there is movement of social science scholars in the opposite direction.

2.1.2.3 Social Determinants of Health

Within public health, social determinants of health is a common approach which, like rights-based approaches, emphasises the impact of inequity on health. Contextual in nature, social determinants of health identify the impact of social and economic factors on health outcomes, including gender (Farmer 1999), poverty, power (Farmer and Gastineau 2005, 73-94) and social class (Marmot, Kogevinas, and Elston 1987, 111-135; Lynch and Kaplan 2000, 13-35). This area has gained increasing attention in recent years, with the World Health Organisation (WHO) establishing the Commission on Social Determinants of Health (CSDH) in 2005. In 2008 the Commission published *Closing the Gap in a Generation: Health Equity Through Action on the Social Determinants of Health (Closing the Gap)* which noted that “[p]utting right [...] inequities ... is a matter of social justice” (Commission on Social Determinants of Health 2008, 1-2).

Despite the many obvious linkages and overlaps between social determinants of health and rights oriented approaches to health, there has been little dialogue between the two (see: Chapman 2010, 17-30; Hunt 2009, 36-41). As Chapman and Former Special Rapporteur on the Right to Health, Paul Hunt note, comprehensive reports like *Closing the Gap* make limited connections

⁸ Farmer and Gastineau, for example state, “[w]e need to make room in the academy for serious scholarly work on the multiple dynamics of health and human rights...” (Farmer and Gastineau 2005, 77).

between the two (see: Chapman 2010, 17-30; Hunt 2009, 36-41). Hunt comments that “[d]espite the multiple, dense connections between social determinants and human rights the report’s human rights content is disappointingly muted” (Hunt 2009, 36). Situating this disjuncture in a broader context, Chapman states that “work on the social determinants of health has rarely acknowledged the potential contributions of a human rights approach” while rights-based approaches have similarly failed to “engag[e] in a meaningful way” with social determinants (Chapman 2010, 17).

The three areas discussed above identify some of the possible sources of rights-based discourse on health more generally, and HIV specifically. These sources are predominantly high level, engaging the state, UN agencies, and drawing on specific disciplinary expertise including medicine, public health and law. But how do such global conversations trickle into locally situated civil society advocacy? How and why does a discourse emerging from specific circumstances of the western HIV pandemic filter into the very different epidemiological and social context of the African pandemic?

2.1.3 Linking Concepts with Action

One of the ongoing challenges with discourses of human rights and health, is the disjuncture between concept and practice. Theorists and practitioners have tended to occupy different spaces both theoretically and physically. This disconnect has led to challenges in theory and application.

As Freeman notes:

[t]he concept of human rights presents a challenge... It can seem remote from the experiences of human beings. The analysis of the concept of human rights, therefore, must be combined with a sympathetic understanding of the human experience to which the concept refers (Freeman 2011, 3).

Similarly, Anand Grover, current U.N. Special Rapporteur on the Right to Health has commented, with reference to health, that we need to focus on experiential components, stating:

[w]e need to pay more attention to the content of the right to health as it is experienced by communities. The right is not only an abstraction to be argued about by academics or clever lawyers. It's a vital part, a living part of people who enforce it themselves (Grover 2009, 1-3).

Finally, Mark Heywood, a South African lawyer and activist long involved with the AIDS Law Project and Treatment Action Campaign has urged for an acknowledgement of the critical role that activists can play in the meaningful achievement of these goals, and in translating theory into practice. He states:

[w]e need to see the level of activism by civil society as a key social determinant of health. The fight for health should be a central pillar of all movements for social justice and equality, not in the abstract, but for the specific goods, institutions, demands and resources that will realise the right to health (Heywood 2011, 1).

Focusing on “people who enforce it themselves” in the form of activists often themselves profoundly affected by HIV, this study endeavours to understand civil society as actors who choose to employ rights as a technique or strategy in relation to HIV.

2.1.4 Civil Society

As an actor, civil society's function in relation to the state is conceived of as a counterbalance, a bulwark against the state (Gellner 1994), a support for the state, and sometimes a component of the state. Its component parts can be understood as explicitly delineated and fixed, or fluctuating to balance against varying threats (Kaldor 2003, 47-48). It is, as Keane suggests intimately tied up with both who we are and who we hope to be, noting in a commentary on Gellner, “we are the fruit of what we must desire and endorse” (Keane 2004, 44).

While much has been written on civil society, the vast majority of this literature is European or North American in origin, leading to questions on the utility of this concept in a broader context, with some arguing that the “current vogue [is] predicated on fundamental ethnocentricity” (Hann and Dunn 1996, i). This study takes the existence of African civil society as given, and, rather than intending to provide an overall assessment of the nature of African civil society, seeks to examine the actions of a particular segment of this sector. I seek a conception of civil society that is concrete and operationalisable, a reality rather than an “ideal” (Seligman 1992) and both, as Lewis puts it “useful to think with” and “useful to act with” (Lewis 2002, 570). As Opoku-Mensah argues, earlier debates about African civil society have “now given way to a general acceptance of civil society as an integral part of the conceptual, policy and, and institutional landscape of [Sub-Saharan African] countries” (Opoku-Mensah 2008, 77). He notes that “the lack of contestation” in the four countries he studied (Ghana, Sierra Leone, Uganda, Togo) around civil society parameters indicates “not only an acceptance of the concept, but a similarity in the historical trajectory and evolution of civil society” in the region (Opoku-Mensah 2008, 77). This project draws on these familiar parameters, referenced above and affirmed by the Civicus civil society index, locating civil society as “the area outside of the family, the state, and the market where people associate to advance common interests” (Civicus n.d.).

While civil society itself can be amorphous and include spontaneous events such as uprisings and protests and disorganised groups of people, this project focuses on the formalised civil society groups known as non-governmental organisations. These named organisations with specified mandates, objectives and activities are comparable across cases and more likely to explicitly adopt advocacy strategies and frames. Less formalised groups are often more issue-specific and issue-driven, and thus are less likely to reflect changes over time or resonance of frames with

institutional identity. Such groups are also more diverse, and have a more fluid membership. In contrast, NGOs usually have an office, some combination of paid staff and volunteers or members, and have a clearer sense (while still not absolute) of where organisational boundaries begin and end. The NGOs studied here are all African-based rather than branches of international organisations, but do predominantly, as is the case in many parts of the developing world, receive their funding from outside of the country. This project takes the perspective that acknowledging and examining this reality is preferable to viewing it as grounds for exclusion. These organisations are significant players and are too seldom examined as legitimate local actors drawing on international connections (rather than outside actors drawing on local connections).

As with civil society in general, for African civil society the relationship between the state and civil society is a key area of discussion. In the African context, civil society rose to prominence in the 1980s when it became an important concept in the discourse around development (Opoku-Mensah 2008, 75). In contrast with dominant European and North American conceptions of civil society, however, in this instance civil society was not viewed primarily as a bulwark against the state, but actually part of the state building process (Bratton 1989). The line between the state and civil society may also be unclear, where “lower state salariat, teachers, junior civil servants, even junior military officers – double as state functionaries and popular intellectuals and articulate popular aspirations” and (Hutchful 1995, 65) “many organisations and interests normally associated with civil society and the private sphere fall into the state and parastatal sector” (Hutchful 1995, 65, 69). While the relations between state and civil society in Africa are often “blurr[ed]” and contested, and may be understood as nation building, as oppositional, or as

operating in different spheres of society, these models all hold a “basic false assumption of the existence of a vertical state/society opposition” as “[p]ower in Africa has long been exercised by entities other than the state (Lewis 2002 579, 577). In my view both depictions are accurate, though their exact fit varies significantly by country. The line between civil society and state is often somewhere permeable, particularly in smaller states with a smaller pool of activists, intellectuals and agitators to draw from. Movement between these sectors is facilitated in some cases by an internal solidarity forged in the anti-colonial struggle during which activists became government officials. But these permeable borders do not reflect state omnipresence or necessarily strength or capacity and, as Lewis notes, the power-wielding entities are varied, meaning that civil society advocacy may have a variety of targets both within and outside of the state. In some ways highlighting this phenomenon, in the contemporary period, there has been an “NGO-ization of civil society, where donor support resulted in the unprecedented growth of NGOs in response to the African development crisis” (Opoku-Mensah 2008, 78). This led “outside policy-makers” to understand African civil society as “a set of development NGOs” predominantly funded from outside of the state and in some cases “effectively taking over some of the state’s functions in health and education” (Lewis 2002, 577-578).

Literature on civil society in Africa focuses predominantly on determining its nature, evaluating its relationship with the state and examining international connections, influences and donors. These important considerations focus more on what civil society is than what it does as a specific actor on particular topics. This leaves gaps in terms of understanding how civil society groups interact with the societies in which they are located, how they might seek and succeed at influencing state and non-state actors, and how they function as organisations.

2.1.5 Framing

Framing offers some insight into the internal world of civil society groups, as well as how they might seek to contextualise their objectives in line with social, political and cultural discourse. Framing as a concept has experienced a surge in popularity since the 1980s (Benford and Snow 2000, 611, Zald 1995, 261), with “fram[ing] issues” now described as the “job of nonstate actors” such as civil society (Wong 2012, 8) and seen as “a central dynamic in understanding the character and course of social movements” (Benford and Snow 2000, 611). Zald contends that in relation to social movements framing is “a substantial break with past conceptions of ideas in movements which tended to emphasise their embeddedness in community” and a move which “has served to reemphasise the central importance of ideas and cultural elements” (Zald 1995, 261).

Benford and Snow argue that framing is an “active, processual phenomenon that implies agency and contention at the level of reality construction,” noting that frames can be diagnostic, prognostic or motivational (Benford and Snow 2000, 614, 616). Framing consists of “conscious strategic efforts by groups to fashion shared understandings of the world and of themselves that legitimate and motivate collective action” (Snow as cited in McAdam, McCarthy and Zald 1995, 6).

In their overview of the field McAdam, McCarthy and Zald include “framing processes” as one of three areas of consistent emphasis across geographic and ideological divides among social movement theorists (McAdam, McCarthy and Zald 1995, 2). Framing is an ongoing rather than one time process with frames “continuously being constituted, contested, reproduced, transformed, and/or replaced” (Benford and Snow 2000, 628). Analysis of frame emergence and selection includes a focus on both motivations for and contexts of frame selection including

drawing on “culture as a toolkit” (Swidler 1986, 277) and utilising the “cultural stock for images of what is an injustice, for what is a violation of what ought to be” (Zald 1996, 266).

Benford and Snow identify three factors as critical in “affect[ing] framing processes and the character and continuity of the resulting frame [...]: political opportunity structure, cultural opportunities and constraints, and the targeted audiences” (Benford and Snow 2000, 628). Zald highlights six features: (1) cultural construction, (2) the “construction of cultural contradictions and historical events,” (3) “framing as a strategic activity,” (4) the competitive process of frame selection, (5) the role of the media in dispersing and legitimating frames, and finally, (6) the interaction between political opportunity and mobilisation and their impact on frames’ effectiveness (Zald 1995, 261). Diani examines Zald’s final contention focussing on the impact of external factors on frame success through a typology categorizing the interaction between two variables: “opportunities for autonomous action within the polity” and “opportunities created by the crisis of dominant cleavages” (Diani 1996, 1057). Building on what he terms a “reformulation” of Tarrow’s definition of opportunity structures (Tarrow 1995, 41-61), Diani posits that “one can expect mobilisation methods to be more or less successful in different political settings, depending on their congruence with the master frames dominant in a given political phase” (Diani 1996, 1057).

Framing literature offers significant exploration of the nature of frames, the function of frames and the processes of framing. However, it provides less insight into the “why” of frame selection, despite presenting several possible frame sources in the form of social context, political opportunity and “progenitor movements” (Zald 1996, 269). This is a particularly significant omission in the context of HIV advocacy where rights may not be a common culturally-located

frame, nor one associated with political opportunity and resonance. While the framing literature does explore internal organisational dynamics, it does not address personal relationships with or belief in frames. Frames are typically aimed at groups of people, seeking to spur mass or collective action rather than individual response. Similarly, strategic or impact-oriented framing processes tend to be oriented at influencing government offices and at public mobilisation rather than individual behaviour.

2.2 Literature and Hypotheses

Having situated the research puzzle and defined and discussed key concepts, the chapter now shifts to examining possible explanations. This is a theory-building project entered into due to a fascination with the unexpected and significant use of rights in HIV advocacy in contrast with the reliance of most health advocates on frames of public health and development. This research explores a new and unexplored area of study spanning several fields as discussed above and, as such, is not structured as a direct response to or critique of existing theory but as a project of theory construction. While theory testing is structured around a statement expressing an explanation and involves examining the general validity and accuracy of that statement, theory building aims to explain a phenomenon by observing actors and events based on an initial list of potential propositions, and with a goal of developing hypotheses for testing across other cases and issue areas (George and Bennett 2005). Consequently, this project began with a question, (why do civil society organisations choose to frame their claims as rights?), and with several possible explanations emerging from the literature.

2.2.1 Explanations from the Literature

Literature in the areas of human rights, social movements, and framing suggests a number of possible explanations for the puzzling use of rights by African HIV activists. Drawing on this literature, and on several years' experience working on human rights and HIV in this sector, I began this research with some possible explanatory factors in mind which shaped the questions that I asked in interviews and the type of information I sought. During the progress of my research, my semi-structured interviews uncovered additional possible explanatory factors which contributed to my exploration of the topic. In an iterative process the two sets of explanatory factors listed above were developed into hypotheses putting forward possible answers to the research question. These hypotheses cluster around three broad areas: intra-organisational factors, external contextual factors, and factors relating to perceptions or expectations of impact. In short, these hypotheses indicate that organisations may choose rights because of who they are, where they are, or because of what they believe rights do.

2.2.1.1 Intra-Organisational Factors

2.2.1.1.1 Personal Belief

Within organisations, the beliefs of personnel may hold a strong influence on the selection and use of the rights frame. Personnel who are 'true believers' hold a strong affinity to the intrinsic value of human rights, and as a result are more likely to be consistent in their use of rights across topic areas. Rights appear qualitatively different than many other frames with respect to the level of personal allegiance they can generate (see, for example, Hopgood 2006). They hold strong "normative power" with the ability to construct "what is considered as right and wrong conduct" (Forman 2008, 39-40, 41). Commenting on the common linguistic roots, and idiomatic

interplay between the words “rights” and “right,” one author aptly captures that for many, rights are tied not only to what is just, but also to what is accurate or true (Forman 2008, 41).

Although not typically depicted as such, rights are sometimes described as a strong belief system that holds some similarity to religious belief (Hopgood 2006; Reader 2003, 41-51). Peter Benenson, founder of Amnesty International stated, for example, that the group existed “to give him who feels cut off from God a sense of belonging to something greater than himself, of being a small part of the entire human race” (as cited in: Buchanan 2002, 593-594). Such expressions suggest that a belief in rights may provide an important linkage to others and reflect a particular understanding of their connection to and responsibility toward others. In exploring belief as a motivator for frame choice, it is important also, however, to recognise the possibility of ‘strategic belief’ or ‘belief of convenience’ where an articulated passion for rights may be viewed as useful in some way, or may follow experience of this frame as a successful strategic tool. This distinction is useful in clarifying whether the impetus for rights choosing is an internal belief, or whether rights use is actually fueled by strategic considerations such as donor preference or government rhetoric.

2.2.1.2 Extra-Organisational Factors

2.2.1.2.1 Rights Context

Advocacy groups exist in and respond to the contexts in which they are located. Consequently, national, regional and continental human rights norms, perspectives and practices are an important factor to explore when examining why groups choose to employ rights in their advocacy. In the African context, there is evidence of strong legal affiliation with rights and local grounding of the concept, as well as contestation of the term as foreign and inapplicable.

Despite tremendous diversity on the continent, there are indications of African human rights norms particularly in the legal sphere. These are implied through treaty ratification and codification through the United Nations and African Union, topical clusters of dialogue that suggest key issues in relation to African human rights, and commonly cited indigenous philosophies, particularly that of *botho/ubuntu*. African states have a high level of participation in global human rights instruments (Heyns and Viljoen 2004, 132-133), despite exclusion from initial international-level development and codification of human rights due to colonialism. As noted earlier, African Union (AU) codification of human rights includes a strong reflection of international standards alongside specific regional emphases on collective rights.

Beyond the law, African perspectives on human rights place greater emphasis on collective rights and group-oriented approaches to rights. London argues that rights must be understood as a vehicle to achieve collective equity and, as such, “locate[d] ... in a group context, rather than in a consumerist mode, in which the individual is the active agent and rights holder” (London 2003, 46, see also London 2007, London 2008). In addition to greater attention paid to collective over individual rights, socio-economic rights have greater prominence in African human rights discourse than they do in the global north. Human rights is often paired with concepts such as development (Tlaluka 2004, 109-119, Osinbajo 2004, 120-128, Veney 2004, 173-190), political economy, and ‘belly politics,’ with some arguing that poverty, and its alleviation should be at the centre of any discussion of human rights in Africa (Tlaluka 2004, 119). In the South African context these challenges increasingly involve the “poor majority” drawing on activism and the law to “challenge non-delivery of services and public policies” (Johnson and Jacobs 2004, 100), an approach that emphasises the infrastructure that is vital for enjoyment of second generation

rights. The two groups of rights, however, are not discretely compartmentalised, nor, as was the case in the Asian Values debate (Wiessala 2006, Sen 1997) is there a dominant argument that socioeconomic rights must precede civil and political rights. Indeed, the recent “ascent” of rights language dates to the 1990s (Halsteen 2004, 103) in the context of dramatic political transformation on the continent, including the end of apartheid and widespread democratisation (Zezeza 2004, 1).

In the formal contexts of academia in Africa, human rights are overwhelmingly dealt with from a legal perspective and in colonial languages. In activism circles the concept has a much more varied existence, in both conceptualisation and language. As Zezeza notes, a “linguistic conundrum” is “at the heart of the drive for human rights in Africa” due to the “continued supremacy of European languages and the relative marginality of local languages in official human rights discourse” (Zezeza 2007, 494). One concept that is sometimes understood as an equivalent, proximal, indigenous or alternative conception of human rights is that of *botho/ubuntu*,⁹ which is translated as, “personhood” (Mmualefhe 2007, 1), “humanhood” (Mmolai 2007, xi) or “humanbeinghood” (Gaie 2007, 30). While the concept exists in many parts of Africa, and is claimed by some as pan-African (Kamwangamalu 1999, 24-41), it is most prominent in southern Africa and particularly in South Africa. The 1997 South African Government White Paper defines the concept as:

Each individual’s humanity is ideally expressed through his or her relationship with others and their in turn through a recognition of the individual’s humanity. Ubuntu means that people are people through other people. It also acknowledges both the rights and responsibilities of every citizen in promoting individual and social well-being (as cited in: Louw 2006, 161).

⁹ Botho is the Setswana term, ubuntu is the Xhosa and Zulu term.

Ubuntu shares some common components of human rights, in that it potentially applies to all and involves treating others with dignity. Indeed, some argue it is simply a local version of universal conceptions of virtue, dignity and proper behaviour (Gaie 2007, 34) while others describe it as a “distinctly African rationale for the ways of relating to others” (Louw 2006, 171, see also: Kamwangamalu 1999, 24-41). Viewing the individual as socially defined and embedded, the concept is sometimes contrasted with a more autonomous and individually-oriented conception of human rights (Cobbah 1987, 309-331).

Levitt and Merry identify a tension between local and international frames as important and necessary (Levitt and Merry 2009, 457). They argue that rights need to be seen as international in order to be “politically powerful” but must also “resonate with existing ideologies” in a local context in order to be adopted and useful (Levitt and Merry 2009, 457). As an advocacy issue, they similarly identify a dilemma whereby groups that use rights frames that mesh more easily with pre-existing approaches “are more readily accepted but represent less of a challenge to the status quo” (Levitt and Merry 2009, 457-458). In examining the interaction between international norms and local politics, Checkel notes that insights from both liberals and constructivists are correct, with “norms sometimes constrain[ing]” by affecting incentive structures and “sometimes constitut[ing]” the “identities and interests” of actors (Checkel 1997, 474, 473) in the domestic context.

As this study examines organisations working at the local, national or regional level the focus of comparison with respect to context is along these lines (primarily national/regional). An emphasis on the geographic context suggests that this factor is important in two key ways. First, the existence of a strong rights discourse in the national or regional setting allows for regular

exposure to the language of rights, increasing the odds of adoption. Second, where rights are a common discourse, groups may choose it because it is understood by and resonates with those whom they hope to influence.

2.2.1.2.2 International linkages

Beyond national borders, international linkages also allow for exposure to new ideas and norms, and provide opportunities for networking, collaboration and joint campaigns that may offer reasons for the use of common language. Over the past twenty years there has been a dramatic increase in the number of human rights organisations (Tsutsui and Wotipka 2004), as well as in the scope of issues addressed using the human rights frame. Beginning with a call to mainstream human rights in all UN programming as part of the 1997 Program for UN Reform, the UN adopted a ‘rights-based approach to development’ which both propelled and reflected this linguistic change, serving to erode the distinction between first and second generation rights discussed earlier. In the HIV sector, as noted earlier, globally rights also became a prominent discourse. As a result, even in contexts where rights may not have been a dominant discourse locally or regionally, groups encountered rights language through networks and international connections.

Transnational lines of transmission include interaction and exposure to other groups in the international community who have begun using particular languages, espousing particular ideologies or value frames, or abiding by particular practices (Hance 1973, 2-4; Magumbane 1982, 8-10). This can include transmission through “transnational linkages” (Johnston 1996, 35) including formalised international organisations (Checkel 2007), transnational advocacy networks, or “epistemic communities” (Haas 1992, 1-35) where ideas are exchanged via repeated

interactions among experts or practitioners in specific fields. Non-governmental organisations have multiple opportunities for many types of interaction and exposure to new ideas including regional and international meetings and conferences, coalitions, international aid workers, and interaction with donors.

The process of adopting new ideas and norms of behaviour can occur through mechanisms such as “socialisation,” whereby repeated interaction with particular ideas results in their adoption (Checkel 2007). This can include learning, through which “a shift along the dimensions of the central paradigm [occurs] as new information leads decision-makers” to alter their strategic preferences and behaviour (Johnston 1996, 33-35, see also Checkel 2005). It can also occur through non-rational mimicry, where specific practices are observed and imitated, shaping organisations in the process. Boli, Thomas and others describe actors as “constructed and motivated” by particular frames, where “nature, purposes, behaviours” are “subject to redefinition and change as the frames themselves change” (Boli and George 1999, 13). In this context, actors “enact[...] cultural models that are lodged at the global level and linked in complex ways to other levels of organisation, with increasing penetration of even the most peripheral social spaces” (Boli and Thomas 1999, 5). Bob argues in his study of the role of international norms in attempts to change the caste system in India that “rhetorical changes played a key role, as Dalits moved from their long-standing focus on caste-based discrimination to a broader framing within the more internationally acceptable terminology of discrimination based on “work and descent” (Bob 2007, 167). This change in frame enabled mobilisation by linking domestic struggles in India to the United Nations human rights system, changing interpretations and applications of critical components of the Convention on the Elimination of All Forms of Racial Discrimination, and linking internationally to other groups facing similar struggles (Bob

2007). The rights frame moved a particular situation relating to South Asian and Hindu cultural and religious practices, to an international human rights violation with parallels in places as varied as Japan and West Africa (Bob 2007, 167-193). Exposure to international ideas, however, does not necessarily result in their adoption and, alternatively, can reinforce or provoke locally-grounded counter arguments or arguments of foreign imposition. The most striking example of a rejection of an international norm in the HIV sector is the lengthy period of denialism in South Africa where government leaders argued that anti-retroviral treatment in use elsewhere was counterproductive and harmful (Kravstov 2009). In such situations domestic groups may want to align themselves with local or government approaches, or to distinguish themselves from questioned international norms and practices.

2.2.1.2.3 Organisational Niche

Organisations may also choose their frame based on the nature of the civil society sector, and their position within it. Carpenter argues that the selection of topics for campaigns by civil society groups is both under-examined and complex, noting that “conditions for issue adoption are constituted by dynamics across, rather than primarily within, issue networks” (Carpenter 2007a, 643). She finds that attributes, graftability and visibility are important but insufficient factors in explaining the uptake of issues by activist groups (Carpenter 2007a, 663). Instead, she highlights factors relating primarily to network dynamics as pivotal. She argues that organisations examine:

whether or not the issue fits their ideational “turf” relative to other networks;
how it will affect their existing efforts and those of their allies in adjacent issue networks;
and how much consensus can be forged with those allies on a suitable advocacy frame
(Carpenter 2007a, 663).

Bob addresses some similar ground, noting that the coherence of ideational constructs relative to international bodies and potential domestic and international allies can be critical in how and why groups address particular issues (Bob 2007).

2.2.1.2.4 Donors

Donor support is integral to the survival of non-governmental organisations, in most cases providing the bulk of their budget. Although in the African context, as in much of the developing world, the majority of funding comes from international donors, this factor is both a domestic and international one as it also includes government support and regional donors. All donors support civil society for a reason, often holding an over-arching goal of changing or contributing to the country in which these groups operate. Supporting non-governmental organisations is understood as a project of poverty reduction or development (Collier and Dollar, 2002), democracy assistance (Carothers 1999, Sundstrom 2006, Diamond 1994), investment in social capital (Putnam 1993), or as a way to improve human rights outcomes (SIDA 2011). Where donors are branches of foreign governments, they usually form part of development assistance and fit with specific foreign policy objectives. Where donors are northern NGOs, such groups often receive much of their own funding from their own governments and have a mandate to promote specific objectives (see Agg 2006) in what has been termed the “financial aid chain” (Oller 2006). Simply put, donors give money with the expectation of an outcome which they define in their own terms. They may aim to change the society through support of non-governmental organisations or to influence the organisations themselves. Even where changing an organisation may not be a goal, donors may hold influence on the topics on which these groups work through funding incentives (Sundstrom 2006, 170), may influence the ways in which they work through length of funding cycles and reporting expectations and procedures

(Oller 2006, 35, Bornstein 2006, 54), may influence the networks groups have access to (for example hosting fora for recipient groups) and the approaches that they use. Therefore, it is logical to expect that over time groups receiving donor funding may become more like their donors, adopting common terminology and advocacy language.

Rights have becoming an increasing popular frame in the donor community since the 1990s (see Nelson and Dorsey 2008, 3, Kindornay, Ron and Carpenter 2012, 472) with a multiple of donors espousing a “rights-based approach to development” (Kindornay, Ron and Carpenter 2012). Reflecting on this reality, Kindornay, Ron and Carpenter put forward the hypothesis, that “[r]ights-based donors seek like-minded NGOs, meaning that NGOs that do not transition to the rights-based paradigm will face funding cuts” while those who do will receive more funding, and those emerging into the sector will “seek rights-based funds” (Kindornay, Ron and Carpenter 2012, 488). Examining funding of two rights-based movements in Russia, Sundstrom notes that while donors have “without a doubt ... dramatically shaped the kinds of activities” (Sundstrom 2006, 170) that NGOs engage in through their funding, donors’ ability to wield influence is constrained by local factors which include whether political structures are supportive as well as the extent to which donor messaging meshes with local values (Sundstrom 2006, xv). She notes that while “foreign donors have influenced the capabilities, activities, and language of Russian NGO activists,” this influence is variable “depending on the local political environment that NGOs encounter, and across issue areas, depending on how compatible transnationally promoted principles and norms are with widely accepted Russian norms” (Sundstrom 2006, 169). Examining aid in a broader context, Carothers finds that funding can “do little to change the fundamental social, economic, and political structures and conditions that shape political life in

other countries” (Carothers 1999, 351) and that such investment must be understood as a “long – term, uncertain venture” (Carothers 199, 351).

Additionally, several structural features stand to mediate the power of donors. First, there has been a trend towards project-based rather than operational funding (Birdsall and Kelly 2007, Kelly and Birdsall 2010). This means that recipient groups tend to have numerous funders, often with differing areas of focus, which may serve to dilute the influence of any one particular donor over organisational frame. Second, recipient groups with strong clear mandates may be selective and set their own limits when choosing when to work with particular donors (Bornstein 2006, 57). Finally, groups may also engage in a shallow way with donor expectations. The “acquisition of transnationalised language does not always lead to actual use of the techniques or belief in the methods” (Sundstrom 2006, 171). Organisations may exaggerate claims (Bornstein 2006, 54-56) in order to retain funding, or use one frame when interacting directly with donors and another with communities (see Sundstrom 2006, 171).

2.2.1.3 Impact

Finally, there is the proposition emerging from the literature that civil society organisations choosing rights as a dominant frame do so because they believe that rights result in some form of impact. This impact can occur at a number of different levels. Here I examine two different forms of impact: public mobilisation and government responsiveness.

2.2.1.3.1 Public Mobilisation

As a mobilisation tool, rights are an attractive concept and linguistic device for a number of reasons. Because of their universal applicability, they call upon ideas of unity and solidarity and,

as such, are useful as an inspiring, enraging, empowering and unifying rallying call. Levitt and Merry argue that rights when viewed as a mobilising tool is “fundamentally different” than viewing rights as law (Levitt and Merry 2009, 460), noting that for activists a benefit of the term is that “the meaning of human rights is fluid and open to grass roots activism” where it can have legal, non-legal, international and local meanings and activists can “seize these ideas and wrestle with them ... mak[ing] them something new” (Levitt and Merry 2009, 459). Because of how integral process is to the use of rights, the process of adopting rights may also require a level of collaboration and mobilisation. Yamin posits that process is an integral part of accountability, noting, for example, that this “requires fostering coalitions to mobilise consciousness and effective social action, in conjunction with or independent of legal strategies” (Yamin 2008, 13).

2.2.1.3.2 Government Responsiveness

Finally, civil society organisations may choose to use rights in advocacy because of the link between rights and accountability at the level of government. Yamin contrasts this with other approaches, particularly those based in charity, noting:

Compassion is undoubtedly a great virtue. But it is also notoriously unstable and, historically, reliance on it has ill-served the interests of the oppressed. ... [U]nfortunately, failures of beneficence and “compassion fatigue” do not trigger accountability; human rights violations do (Yamin 2008, 1).

Yet there remains disagreement about what accountability means and, even where definitional agreement exists, “it is not always clear how ... ‘accountability’ might be ensured in practice,” particularly with reference to second generation rights and differential standards based on ability (Yamin 2008, 1). While Yamin suggests that human rights strategies are not limited to litigation, her focus is overwhelmingly legal. She discusses the interaction, stating that “[f]or good – and for ill- our current notion of rights ... is, to a large extent, the product of courts’ actions and the

rise of constitutionalism as a principal form of social transformation in the second half of the 20th century” (Yamin 2008, 5). She notes that from the early 1990s onwards “courts throughout the world have increasingly enforced access to health goods and services” but that this significant change has received little attention from the field of public health (Yamin 2008, 6).

Unlike other frames, including those based in development, charity or religious conviction, human rights approaches do often provide for at least a theoretical, and sometimes a very practical connection to legal recourse (see for example: Gloppen 2008). In some cases the victory may be purely symbolic, but in others it has practical tangible consequences. Simmons chronicles changes in Japanese laws around gender as a result of the ratification of the CEDAW treaty, for example (Simmons 2009) and Yamin cites Costa Rican reports that an 80% drop in HIV-related deaths was linked to a decision of the country’s constitutional court on anti-retroviral drug provision (Yamin 2008, 6). Forman argues that accountability, through judicial remedies, is a key operational facet of the human rights frame with reference to trade rules and the pricing of HIV-related drugs (Forman 2008, 45-46). She states that, “rights-based advocacy, litigation, and discourse have significantly shifted government policies, corporate pricing, and even trade rules related to AIDS medicines” (Forman 2008, 37). Forman uses campaigns for HIV-related drugs as an “iconic rights experience” making parallels to the American civil rights movement, arguing that these forerunners may both foreshadow and pave the way for rights-based campaigns and litigation on drug access more generally (Forman 2008, 43).

While rights advocates emphasise the value that the approach puts on process and accountability, many of the same individuals comment with concern that there is often significant difficulty in operationalising rights claims (Gruskin and Daniels 2008, 1577; Yamin 2008). This is

particularly the case with respect to the less clearly justiciable economic, social and cultural rights as discussed earlier due to weaker language of obligation and weaker structures of enforcement.

The quest for enforceable rights claims with respect to health is not helped by the argument that, with its lauded emphasis on process, a human rights approach may be less clearly goal-oriented.

A human rights approach sets out a process but does not determine a preordained result. It requires analysing which rights and which populations would be positively or negatively affected by each intervention. Specific attention must be paid to who would benefit most, and in what ways, from each intervention, and who would be left out (Gruskin and Daniels 2008, 1575).

This lack of focus on outputs, is tied to the most challenging critique of all: that a human rights approach is unadvisable because it simply does not work. Hafner-Burton and Ron maintain that while the human rights movement has been effective at “persuading ... global elites,” its impact on the actual enjoyment of human rights is at best unclear, pointing to a disconnect between “gloomy” findings of quantitative researchers and more optimistic ones by those undertaking a qualitative approach (Hafner-Burton and Ron 2009, 388), a point contested by Risse, Ropp and Sikkink (Risse, Ropp and Sikkink 2013). Hafner-Burton and Ron argue that, while not entirely without value, the “human rights discourse may be thriving, at least in part, for reasons unrelated to impact” (Hafner-Burton and Ron 2009, 360). Examinations of the effect of formal, legalised human rights approaches in the form of the ratification of international human rights treaties have similarly come up with findings ranging from optimistic to inconsistent, inconsequential, and outright discouraging. Simmons’ positive correlation between treaty ratification and respect for human rights (Simmons 2009) stands in marked contrast to Hathaway’s 2002 determination that “not a single treaty” showed consistent association between ratification and improved human

rights standards (and several where ratification appears to be correlated with deterioration) (Hathaway 2002, 1940). In the health sector Hathaway's findings have been confirmed in part by a 2009 study examining health outcomes and relevant human rights treaty ratification which found "no significant association" between the two (Palmer et al. 2009, 1987). Not all researchers

2.2.1.4 Hypotheses from the Literature

The literature discussed above suggests a number of possible explanatory hypotheses:

- 1) Organisations that choose rights as a primary frame do so because personnel (particularly leaders) hold a strong personal belief in human rights.
- 2) Organisations choosing rights as a dominant frame do so because they exist in environments where rights discourse is prominent domestically, and adopt it through a process of socialisation. Employing rights enables them to speak a common local language of advocacy that is readily understood.
- 3) Organisations choosing rights as a dominant frame do so because they are closely and regularly linked to international groups that employ rights, and through repeated interaction adopt rights language through a process of socialisation. Employing rights enables them to speak a common language with their international allies.
- 4) Organisations that choose rights as a primary frame do so because it allows them a unique niche relative to other organisations.
- 5) Organisations who choose rights as a dominant frame do so because they have persuasive donors who prefer, promote and encourage this frame by providing funding for activities that are congruent with it. Groups choose this frame in order to secure and maintain funding.
- 6) Organisations using rights as a dominant frame do so because they believe that the approach will be successful in mobilising supporters and they anticipate that such mobilisation will effect policy change.
- 7) Organisations choosing rights as a dominant frame do so because they anticipate government will respond to rights-based claims.

2.2.2 Emerging Explanations

As noted earlier, this theory-building project is an iterative process. I began the project with a perception that rights-choosing was primarily influenced by factors outside of the organisation (context and connections) and perceptions of impact. I expected to see impact in the area of public mobilisation and policy change as particularly important motivators for the use of rights in advocacy. As I delved further into the research, it became clear that, in addition to the theories from the literature which I continued to explore, additional possible explanations emerged inductively during field research that I subsequently examined for plausibility and weighed against the evidence. These emerging factors included perceptions of the scope of rights, the role of leadership and organisational structure, and the expectation of individual-level impact. With respect to impact, my initial speculation that some form of individual behaviour change (perhaps resulting in lowered risk behaviours and lower rates of infection) might motivate rights-choosing became a broader concept of individual-level empowerment as a foreseen outcome and impetus for rights in advocacy.

While conducting research it became apparent that there was significant variation in how rights were understood and, particularly in whether rights were conceived of as a broad inclusive frame or as a specific topic or legal concept. I hypothesised that organisations staffed by personnel viewing rights as a flexible mega frame are more likely to use rights as a dominant advocacy frame. Such groups see many topics as falling within the rights frame.

Other factors within organisations that may influence their adoption and retention of the rights frame include their initial mandate, leadership and their organisational structure. Frame choice may also be affected by organisational history, particularly the group's founding mandate. Initial

mandates may place organisations on a trajectory of path dependence where the initial decision becomes reinforced over time by habitual practice, hiring decisions, organisational niche and organisational networks. Bureaucratic and structural characteristics within organisations can influence the selection of new areas of work. Centralised organisational structures allow for more regular interaction with leadership, and for greater consistency in messaging and practice. Where this is centred around a rights oriented leader, this may increase the likelihood of using the rights frame relative to more decentralised structures.

Finally, with respect to language, field research suggested that the targeted impact of advocacy might be at the individual level. Language holds power, and the language of rights in particular may be chosen because it is understood as holding the ability to affect those who engage with it. Engagement with human rights could change how individuals behave, including how they might access health care services. The rights frame may enable target groups to seek healthcare from a position of entitlement and strength.

Reflecting back on the literature, there is a small body of work related to the three areas addressed above. The perspective of rights as a broad, inclusive frame is in line with Levitt and Merry's contention that rights hold "fluid[ity] and open[ness]" (Levitt and Merry 2009, 457-459) that allow it to be applied to most or all of the topics on which the organisation conducts advocacy. Wong has highlighted the importance of organisational structure, particularly the balance between centralisation and decentralisation (Wong 2012, 57). She notes that substance and structure are intimately linked, arguing "the issues that are selected and framed are mediated through organisational structure" (Wong 2012, 62). Examining the internal dynamics of frame emergence, McAdam, McCarthy and Zald note that within contexts of strong organisation these

processes “are held to be more likely and of far greater consequence” (McAdam, McCarthy and Zald 1995, 9) indicating that bureaucratic and organisational structure intersect with the decision and consequences of framing in a number of complex ways.

Barnett and Finnemore highlight bureaucracy in their work on international organisations, arguing that this emphasis, including an understanding of an organisation’s “internal logic” and “behavioural proclivities” (Barnett and Finnemore 2004, 3) provide a useful explanatory window into how an organisation changes. Barnett and Finnemore suggest that an organisation’s initial mandate may not result in path dependence. They state:

Organisations that start out with one mission routinely acquire others. Organisations adapt to changing circumstances in unanticipated ways and adopt new routines and functions....IOs evidence all these familiar traits. They exhibit mission creep. They wander far from their original mandate and into new terrains and territories. They develop new rules and routine in response to new problems that they identify (Barnett and Finnemore 2004, 3).

This analysis raises additional questions for exploration in future research. Do some types of mission experience more creep than others? Do rights function in the same or different ways than other advocacy frames when it comes to organisational change?

Finally, while frame choice is usually explained with reference to organisational or contextual fit, Yamin in her work on rights has explored the idea of “subversive potential” (Yamin 2008, 13). Yamin argues that rights have the ability to greatly influence not only violators, but also those affected by these violations (Yamin 2008, 13). She states, “the accountability that human rights brings to bear converts passive recipients of health goods and services into active claim-holders, and challenges systems in which people are beholden to those wielding power over them with all too much discretion” (Yamin 2008, 13). In contrast with development approaches,

human rights approaches place “emphasis on changing relationships of power” as opposed to being solely concerned with material outcomes (Yamin 2008, 12). As a result, processes are significantly more important in rights approaches – with evidence of meaningful, empowering participation from impacted communities considered critical components of accountability (Yamin 2008, 12).

These emerging explanations and related literature suggest some additional hypotheses:

- 1) Organisations that choose rights as a primary frame do so because personnel (particularly leaders) have an expansive understanding of human rights as a mega-frame that includes most or all of the topics on which the organisation conducts advocacy.
- 2) Organisations that choose rights as a primary frame do so because they have a centralised structure (secretariat – based) which allows for regular interaction with rights-oriented leadership and the development of a rights-based organisational culture.
- 3) Organisations that choose rights as a primary frame do so because they were established with a rights oriented mandate establishing a trajectory of path dependence.
- 4) Organisations using rights as a dominant frame do so because they believe that rights have a distinct and empowering impact on the target groups with whom they interact, enabling them to better claim health care services and transforming the nature of their relationship with the state from one of a passive recipient to one of an active citizen.

2.2.3 Structure of Analysis

As is evident from the discussion above, as a theory building project this research involves generating far more hypotheses than is usual in theory testing, with a goal of exploring and assessing the universe of possibilities in order to construct a theory with explanatory power. The hypotheses put forward are also relatively simple single-step propositions that were expected to serve as argumentative building blocks in the construction of a more complex explanation.

The hypotheses identified both deductively and inductively were grouped into three categories (intra-organisational, extra-organisational and impact), and provide the structure for the

comparison carried out in the empirical chapters. In one instance, two hypotheses were merged into one (belief and scope of rights) as they appeared to be closely connected.

Table 1: Hypotheses

Intra-Organisational	Extra-Organisational	Impact
Organisations that choose rights as a primary frame do so because personnel (particularly leaders) hold a strong personal belief in human rights and have an expansive understanding of human rights as a mega-frame that includes most or all of the topics on which the organisation conducts advocacy.	Organisations choosing rights as a dominant frame do so because they exist in environments where rights discourse is prominent domestically, and adopt it through a process of socialisation. Employing rights enables them to speak a common local language of advocacy that is readily understood.	Organisations using rights as a dominant frame do so because they believe that rights have a distinct and empowering impact on the target groups with whom they interact, enabling them to better claim health care services and transforming the nature of their relationship with the state from one of a passive recipient to one of an active citizen.
Organisations that choose rights as a primary frame do so because they have a centralised structure (secretariat – based) which allows for regular interaction with rights-oriented leadership and the development of a rights-based organisational culture.	Organisations choosing rights as a dominant frame do so because they are closely and regularly linked to international groups that employ rights, and through repeated interaction adopt rights language through a process of socialisation. Employing rights enables them to speak a common language with their international allies.	Organisations using rights as a dominant frame do so because they believe that the approach will be successful in mobilising supporters and they anticipate that such mobilisation will effect policy change.

Table 1: Hypotheses (continued)

Intra-Organisational	Extra-Organisational	Impact
Organisations that choose rights as a primary frame do so because they were established with a rights oriented mandate establishing a trajectory of path dependence.	Organisations that choose rights as a primary frame do so because it allows them a unique niche relative to other organisations. Organisations who choose rights as a dominant frame do so because they have persuasive donors who prefer, promote and encourage this frame by providing funding for activities that are congruent with it. Groups choose this frame in order to secure and maintain funding.	Organisations choosing rights as a dominant frame do so because they anticipate government will respond to rights-based claims.

It is important to emphasise that this project attempts to answer a single positive question (why do groups choose rights) rather than a double-barrelled question examining both positive and negative outcomes (why do groups choose or not choose rights). This distinction is important because the act of not choosing rights is not a simple mirror image of choosing rights. In fact, not

choosing rights involves three questions: 1) why do groups choose not to use rights?, 2) what frame(s) do groups that do not choose rights use instead?, 3) why do they choose the frame(s) they do? This research is focused on explaining the positive choice (why do groups choose rights?) and is structured to theorise an explanation for this positive question. In doing so, it does explore elements of non-rights choosing but does so with the objective of contributing to and strengthening an explanation of rights-choosing, rather than with the goal of developing an explanation of non-rights choosing in parallel.

As I conducted research it became clear that some hypotheses were far more central than others in explaining the puzzle of rights choosing in the HIV sector. To preview the argument briefly, among intra-organisational factors, belief in the rights frame, leadership and organisational structure proved particularly important. Organisations that choose rights as a dominant frame tend to have strong leaders with a firm belief in rights who are able to develop a rights-based organisational culture. Their ability to do so is mediated by organisational structure and the domestic prominence of rights discourse in advocacy. Where rights are not a common national discourse, a centralised organisational structure facilitates the development of a rights oriented organisational culture by allowing for frequent interaction between personnel and leadership. This set up allows such groups to serve as incubators of rights-based advocacy even where they have little outside support for or reinforcement of this frame. In contrast, in settings where rights is a common local language of advocacy, more dispersed membership-based structures can and do support rights-based HIV organisations. The expected impact of rights also emerged as a critical motivator for the use of rights as an advocacy frame, with a strong emphasis on individual-level influence. Groups using rights as a primary frame predominantly explained this choice due to the anticipated impact of the frame on individual behaviour. Such organisations

expected the rights frame to change individual behaviour, empowering people to claim health services from a position of strength. This empowering impact was cited as the primary rationale for the use of the rights frame and its main distinguishing feature in comparison with other possible frames. Other factors examined including donor frame preference, and expectations of government response or public mobilisation, while not unimportant, did not appear to be primary motivators for the choice to employ the rights frame.

The following chapter lays out a research design to examine these hypotheses, using them as tools to contribute to the further construction of theory. The empirical chapters mirror the structure outlined here, conducting a systematic comparison of intra-organisational factors, extra-organisational factors, and perceptions of impact.

Chapter 3: Methodology

Research Question: Why do civil society organisations conducting advocacy on HIV in Sub-Saharan Africa choose to express their claims in the language of human rights?

Investigating the use and non-use of human rights language within HIV advocacy organisations in sub-Saharan Africa is, as noted earlier, a project of theory building. It is attempting to break new ground and to piece together explanatory themes within these groups which could subsequently be tested across a larger number of cases, among new health issues, or in different geographic contexts. The question of why, how, and to what end groups choose to employ human rights language in their HIV advocacy is also inherently a qualitative one. It is an investigation of opinions, intentions and beliefs about language, rights and impact. As such, a qualitative and interview-heavy method is a logical approach in order to uncover the way in which respondents understand their advocacy options and the meaning of these choices.

This chapter aims to situate the selected methodological techniques with reference to the methods literature, to justify the selected methods, and to explain how these methods were applied in practice. The chapter unfolds in four parts. First, I conduct a targeted review of relevant methodological literature. Second, I describe the process of case selection. Third, I outline the process of data collection and analysis. Finally, I indicate limitations, scope conditions and generalisability.

3.1 Methodological Literature

Like theory testing, theory building strives to be systematic, however, unlike the narrow focus of testing, theory building also requires a methodological structure that is open enough to allow for the discovery of new ideas and unexpected explanations. While theory testing is structured

around a known hypothesis, theory building involves an attempt to construct a theory from both known and unknown parts. In this instance this involves a combination of deductive and inductive techniques. As outlined in Chapter 2, this project involved the identification of hypotheses from related literature and field experience. It also entailed the generation of hypotheses through the process of field research employing some techniques of grounded theory.

Deductive and inductive reasoning address the same key steps and concepts but with opposing points of departure. Deductive reasoning begins with theory, and subsequently seeks to examine how and whether that theory is reflected in data. Brady and Collier define the process of deductive analysis as “the use of theories and hypotheses to make empirical predictions” (Brady and Collier 2004, 284). As such, the deductive process is often described as theory testing, with the goal of proving or disproving a theory or narrowing, enlarging or modifying its scope. The deductive process usually takes place in a particular sequence, following the research question with a hypothesised answer (theory) which is drawn from the literature and then tested against data (see King, Keohane and Verba 1994, 12-28). From this perspective, familiarity with literature at the outset is critical and allows for the identification of a research question and theory. Deductive theory is often associated with a positivist perspective seeking to identify laws with broad generalisability. Its value is measured through an “outside test” (Roth and Mehta 2002, 134) that is, the extent to which it is replicable, testable, and falsifiable.

In contrast with deductive reasoning, inductive reasoning takes data as its starting point. Inductive analysis is “[a] method that employs data about specific cases to reach more general conclusions” (Brady and Collier 2004, 291). Inductive logic uses observation to build a theory recognising human’s abilities at “seeing and recognising or matching patterns” (Arthur 1994,

406). Inductive reasoning is often associated with a more interpretivist perspective, where specificity may be favoured over generalisability and meaning or conceptualisation valued over scientific laws (Roth and Mehta 2002, 134).

Grounded theory is one form of research that relies heavily on inductive reasoning. A method of “discover[ing] theory from data systematically obtained from social research” (Glaser and Strauss 1967, 2) grounded theory is a response to what Glaser and Strauss considered a “slight[ing]” of theory development in comparison with theory verification (Glaser and Strauss 1967, 10). This data-driven and derived method is premised on specific, detailed and deep knowledge of cases and aims for fit, relevance, workability and modifiability (Glaser and Strauss 1967). Unlike this project which employs a mix of deductive and inductive methods, some forms of grounded theory seek to avoid exposure to literature prior to research in order to begin research with a clean slate and open mind (see Glaser 1992). Grounded theory is non-linear, taking place as an “iterative process [...] moving back and forth between empirical data and emerging analysis mak[ing] the collected data progressively more focused and the analysis successfully more theoretical” (Charmaz 2006, 8).

Grounded theory’s strengths include strong attention to context and the specificity of cases, through techniques such as observation, field notes, interviews and “thick description” (Geertz 1973). Data is observed and gathered, and then sorted and grouped through processes of coding, conceptualisation, categorisation and finally the development of theory (Glaser 1992). This bottom-up method lends itself to rich data that can “help to forestall the opportunistic use of theories that have dubious fit and working capacity” (Glaser and Strauss 1967, 4). However, because of the subjectivity of these methods, it has also been critiqued as “less like discovery and

more akin to invention” (Thomas and James 2006, 767). In contrast with deductive methods, grounded theory and related techniques are validated through an “inside test” involving the collection of additional detail and data from inside the case rather than through additional cases or broader generalisability (Roth and Mehta, 2002, 134).

Theory development takes place through a variety of methods, including “deductive methods [that can] usefully develop entirely new theories or fill the gaps in existing theories,” “case studies [that] can test deductive theories and suggest new variables that need to be incorporated” (George and Bennett 2005, 111) and the use of thick and detailed description in an “interpretive ... search of meaning” (Geertz 1973, 5). The earliest stage of theory development - the identification of a research question - is the most critical, but is also “less formalised” (King, Keohane and Verba 1994, 14) than other stages of the process and often the least transparent. The impetus for research in a particular area or from a particular standpoint may have “personal and idiosyncratic origin” (King, Keohane and Verba, 1994, 14) but this origin is often “cloaked by the ‘rhetoric of impersonality’ that obscures the people who actually do the research” (Snyder 2007, 1).¹⁰ The origin of ideas can be unpredictable and mysterious. As Popper notes, “there is no such thing as a logical method of having new ideas, or a logical reconstruction of this process” arguing that “[d]iscovery” inherently “contains an ‘irrational element’” (Popper 2002, 8).

In this instance, the research question has clear roots in personal experience. I came to this project with an academic background in human rights, but also having worked with rights-

¹⁰ Snyder borrows the term “rhetoric of impersonality” from Berger (1990, xix).

oriented civil society organisations. I spent two years as a Human Rights Researcher with the Botswana Network on Ethics, Law and HIV/AIDS, an experience which sparked my interest in the use of rights in HIV advocacy and also provided me with background in the topic. From a methods perspective, this early exposure to the subject and context could be considered an informal inductive process where I arrived with little background and few expectations and gradually based on experience and observation developed a preliminary explanatory narrative. This background allowed me to begin my formal examination of this topic with hypotheses derived from personal experience and from the literature, introducing a deductive element. As noted in Chapter 2, hypothesis development then became an iterative process, with additional reflection, refinement, addition and deletion of hypotheses and components of hypotheses throughout the research process. Consequently, this project is a case of a hybrid of inductive and deductive methods. It does not employ pure grounded theory, but does clearly draw on inductive data-driven techniques such as naturalistic observation and semi-structured interviews. Deductive theory-driven elements including systematically seeking information to confirm or refute hypotheses also play an important role. These two forms of reasoning come together through the use of case studies as a primary research strategy.

3.2 Case Studies

All methodological techniques have specific strengths and weaknesses and “[r]esearchers should use each method for the research tasks for which is it best suited” (George and Bennett 2005, 6). George and Bennett argue that case studies are particularly strong in four areas: (1) “achiev[ing] high levels of conceptual validity;” (2) hypothesis generation (see also: Eckstein 2000, Lijphart 1971); (3) examining causal mechanisms (see also: Van Evera 1997); and (4) “modelling and assessing complex causal relations” (George and Bennett 2005, 19-22). Several of these features

make this method especially relevant for this study. First, an examination of rights as a frame requires attention to nuance, language use and intention and “detailed consideration of contextual factors” (George and Bennett 2005, 19, see also Ragin 1987). Second, as a theory building project, I specifically sought methods that would have the flexibility to seek out and assess new ideas and explanations. Case studies are recognised as “particularly useful for theory development” (George and Bennett 2005, 19). Finally, this dissertation poses a ‘why’ question that suggests a complex causal chain.

Case studies allow for rich description and detail (Eckstein 2000, King, Keohane and Verba 1994) providing for a situated and comprehensive understanding of the issues studied. However, their strengths in this area do not mean that their utility is limited to description. Case studies are used for systematic analysis through techniques such as controlled comparison (Van Evera 1997, Mill 1868) and process tracing (Van Evera 1997). The level of depth employed in case studies also reduces the risk of some types of error such as omitted variable bias as researchers are more likely to be open to and exposed to a variety of possible explanations, particularly when employing in-depth or semi-structured interviews. In qualitative research, “error is a prod” pushing researchers to “uncover patterned diversity” (Ragin 1997, 37) and in a case study setting there is an objective to include and explain all cases (Ragin 1987).

Case studies are not without their critics. King, Keohane and Verba view the method as a secondary option when statistical methods are impracticable, arguing that case studies are vulnerable to degrees of freedom problems, have limited theoretical utility and are not generalisable (King, Keohane and Verba 1994). As an intense technique that generally involves a small number of cases, case studies can be vulnerable to selection bias, selection on the

dependent variable and an over-estimation of the causal effect (Geddes 1990). The flip side of a lessened risk of omitted variable bias is that, in their richness, case studies may include extraneous variables.

Some of these problems centre on the trade-off between small and large N studies, and the delicate balance between precision, richness, parsimony and generalisability. Beyond these inherent tensions, some of the critiques of case studies can be addressed. First, degrees of freedom can be addressed by using a counterfactual (Fearon 1991), or increasing the number of cases (Lijphart 1973, King Keohane and Verba 1994). Second, with attention to selection criteria selection bias can be significantly reduced and a deliberate effort made not to select on the dependent variable. In this study, cases were deliberately sought with variation on the dependent variable (use of the rights frame). In this project, case studies are used for both within case and cross case analysis, a technique reflecting a “growing consensus” that such an approach is the “strongest means of drawing inference from case studies” (George and Bennett 2005, 18).

Case studies are a logical methodological choice to examine the question this project proposes. They allow for: a high level of detail, the emergence of new explanations as well as the examination of existing hypotheses, an exploration of meaning in context, and systematic comparison. They provide sufficient detail and breadth to construct an explanation serving as the first building block in the larger quest to explain the reason for rights-choosing among civil society groups working on HIV/AIDS in sub-Saharan Africa.

3.3 Selection of Countries, Cases and Participants

The process of identifying cases and participants was one of nesting, utilising the same logic at three different levels, with each fitting into the other. The units of analysis and comparison for this study are organisations, which are located in the middle of two other selection choices: that of interview participants within the organisation, and that of countries from which to choose organisations. In each case, selection was made with a view to acknowledging both similarity and difference. This was done to control for factors not being studied in order to isolate active variables and, conversely, to allow for variation in order to increase the scope of generalisability.

3.3.1 Selection of Countries

As Mill has argued, it can be useful to intentionally select cases where much of what is not being studied (i.e. other potential explanatory variables) is held constant, so as to isolate the effect of the variable being examined (Mill 1868). Lijphart argues that this can be one justification for area studies, as much in terms of culture, language and regional characteristics can be held constant by focusing on a particular region of the world (Lijphart 1971, 682-693). With an eye to choosing cases with some degree of similarity, all cases have been selected from the continent of Africa. Despite enormous diversity across the continent, this allows for some degree of control with respect to history (nearly every country has a history of colonisation), economic development, and culture (certain continental norms, such as consensus-based decision making, and community-oriented perspectives predominate and are reflected through institutions such as the African Union). As this study examines the use of language, an attempt was made to control this variable to an extent by selecting organisations within countries that have English as an

official language and that have some form of British colonial history.¹¹ All countries studied are ranked either ‘partly free’ or ‘free’ by Freedom House (Freedom House 2012). This classification is relevant to this study as it indicates some room for civil society organisations to operate openly and to conduct advocacy, including advocacy targeting the government. The countries selected do not include some of the continent’s poorest nations, nor do they include areas of conflict or post-conflict (research was not conducted in Northern Uganda). As such, the scope of the geographic areas studied are limited to those situated in Anglophone Africa, where civil society groups operate with some level of freedom in a non-conflict setting.

In order to increase potential generalisability, however, attention was also paid to difference including selecting for variation on potential explanatory variables. Organisations were selected within countries in three different regions of sub-Saharan Africa, namely Southern Africa (South Africa and Botswana), East Africa (Uganda) and West Africa (Ghana). These countries reflect significant variation in HIV prevalence rates, and with respect to government and civil society response to the pandemic including visibility and messaging of campaigns and prominence of rights language. Several countries selected are also known for their specific responses with respect to HIV, including South Africa’s period of HIV denialism and high level of civil society mobilisation, Botswana’s government response, and Uganda’s acclaim for its success in lowering rates of infection. Variation across these features is critical as it allows for analysis of the impact of domestic contextual factors on the organisational choice to use the rights frame in advocacy. In order to briefly situate these countries, and the organisations within them, in

¹¹ Either as a colony or protectorate. All countries are multilingual. South Africa, Botswana and Uganda have English and at least one other language designated as official. Ghana has English as an official language and nine government-sponsored languages.

relation to the topic at hand, the following section provides a short overview of the HIV context, government response and civil society context in South Africa, Botswana, Uganda and Ghana.

3.3.1.1 South Africa

3.3.1.1.1 HIV Context

South Africa has a generalised epidemic, with the first case reported in 1987, it is now the country in the world with the highest number of HIV infected people, with an estimated 5.6 million people living with the virus and an overall prevalence rate of over 17.8% (UNAIDS 2009). Although the first infections reported were among white gay male flight attendants recently returned from the United States, the virus shifted rapidly, becoming a predominantly heterosexual epidemic by 1991 and primarily affecting the majority black population (Avert n.d., see also Karim and Karim 2002). The mining sector became an epicentre of infection, infecting migrant workers from throughout the country and region, who then returned to their home communities on holidays to infect their wives and girlfriends. As with elsewhere on the continent primary routes of infection are through sexual activity (primarily heterosexual) and mother to child transmission.

HIV has a relatively high level of visibility in South Africa, with frequent coverage in the print and other news media addressing a variety of aspects of the pandemic. Billboards observed at the time of research were part of the ‘Brothers for Life’ campaign, targeting men with behavioural slogans, such as “In the game of life always play it safe” and “be a man who takes no chances

and always uses a condom.”¹² The country has a number of media campaigns using tv, radio and other media and platforms to spread HIV education.

3.3.1.1.2 Government Response

While the current government is onboard with international scientific opinion regarding HIV diagnoses, connection to AIDS, and treatment, earlier leadership made international headlines through persistent denial of the linkages between HIV and AIDS and the argument that anti-retroviral (ARV) drugs were toxic and that nutritionally-based interventions including garlic, African potato, beetroot, lemon and olive oil were effective and safer treatment (see: Thom 2009, McGregor 2009, Ndaki 2009). Researchers estimate that the delayed roll-out of ARVs which was justified on related argumentation, was responsible for upwards of 330,000 deaths (Chigwedere et al. 2008, 410-415, Nattrass 2008, 157-176).

ARV roll out eventually began in April 2004 (IRIN 2004) following a court case, illegal importation of ARVs by activists, as well as NGO-led treatment.¹³ Changes in leadership brought the government in line with regional and international approaches, with the Ministry of Health taking the lead, and the South African National AIDS Council (SANAC) taking a coordinating role. Established in 1997, SANAC was reconfigured in the wake of this sea-change. The council is described as having been “formed to strengthen the strong political leadership as well as to ensure inclusion of civil society in the overall response to HIV and AIDS,” and is

¹² August 2010 in Pretoria and Johannesburg, one billboard observed in each location. Billboards listed in Appendix B.

¹³ Medecins Sans Frontiers introduced ARV treatment in Cape Town’s Khayelitsha township.

composed of both government and civil society, with Mark Heywood, a well-known activist affiliated with Treatment Action Campaign and AIDS Law Project becoming deputy chair in 2007 (South African National AIDS Council 2012).

While South Africa has no HIV-specific legislation, the post-apartheid legal framework, and particularly the Constitution play a major role in advocacy around HIV. In contrast with much of the world, the Constitution explicitly includes socioeconomic rights including the right to health, providing some justiciability. It also provides greater standing to international legal commitments, allowing these to be invoked directly. Also in contrast with the rest of the continent, South Africa has revoked its anti-sodomy statutes. The country explicitly includes non-discrimination on the basis of sexual orientation in its constitution and legalised same sex marriage in 2006.

3.3.1.1.3 Civil Society Context

With a history of resistance, a post-apartheid constitution that is “a living document”¹⁴ and a high level of comfort with overt protests, South Africa has a global reputation for activism. In the post-apartheid period, crises relating to service provision “have necessitated a stronger civil society that has found its feet and begun to use the progressive tools of democracy such as the Constitution, to its advantage” (Fleming, Herzenberg, and Cherrel 2003, 24). Although some feel that the level of activism is currently in a lull, by global and African standards it is still a place of frequent demonstrations and loud voices, where “there’s a strike or a threatened strike every

¹⁴Author’s interview, Employee, International NGO, 2 July 2010, Gaborone, Botswana.

month ... because people have the impulse to go to the streets.”¹⁵ Overt activism is almost a first port of call as a response to disputes or disappointments, and is viewed as both legitimate and effective. Civil society in South Africa is widely described as “vibrant” (Fleming, Herzenberg, and Cherrel 2003, Kearsey 2007). The anti-apartheid movement entailed broad-spectrum coalitions uniting diverse aspects of both society and civil society, with umbrella movements bringing together unions and other civil society groups moving towards a common cause. Many of these coalitions persist in the post-apartheid period. Another legacy of the anti-apartheid struggle is the use of human rights language, as a common and widely understood discourse.

South Africa is an important country to examine because it has had one of the highest profile responses to the HIV pandemic, in several distinct ways. The country stands out on the continent for the lengthy period of government-sanctioned denial of the link between HIV and AIDS, which made for a unique and polarised relationship between government and civil society actors. Drawing on the legacy of anti-apartheid protests, and utilising the country’s Constitutional provisions as advocacy tools, South African civil society is particularly active and is grounded in a context with a strong rights discourse.

3.3.1.2 Botswana

3.3.1.2.1 HIV Context

Botswana has one of the highest rates of infection in the world, with a 17.6% prevalence rate in a sparsely populated country of two million people, and prevalence rates of more than 25% among those aged 15-49 (National AIDS Coordinating Agency (Botswana) 2010). The first case was

¹⁵Author’s interview, Employee, International NGO, 2 July 2010, Gaborone, Botswana.

reported in 1985, and the virus spread rapidly, reversing dramatic gains in development, and lowering life expectancy by 25 years (Center for Disease Control, 2001). The virus is viewed as the primary threat to the country's economic progress and stability, and has been framed as a threat of "extinction" (Center for Disease Control, 2001). The pandemic is very high profile, and the country has a generalised pandemic affecting every community, and nearly every family in the country. An often quoted slogan is, "if you're not infected, you're affected."

Billboards observed in Botswana¹⁶ were predominantly soccer themed, in line with the World Cup in adjacent South Africa, and focused on circumcision as a method of prevention. There was a process of cycling through of different messages in the same location, with the soccer themed billboards following sexual network messaging very similar to that found in Uganda, featuring the '*o icheke*' (break the chain) slogan. Alongside these coordinated national campaigns were localised signs erected by municipal governments which tended to have simpler messages such as "stop AIDS and keep the city tidy." While HIV messaging was still quite prominent, there has been a noted decline in visibility from 2005 to 2010, which could be linked to changes in national leadership and leadership priorities.

3.3.1.2.2 Government Response

The epidemic has had a very high profile within the country, with the Former President, Festus Mogae making it an issue of focus, and chairing the National AIDS Committee throughout and beyond his presidency. In contrast with neighbouring South Africa the government took a proactive approach early, and the country was the first on the continent to roll out ARVs (through

¹⁶ Observed in Gaborone and Mochudi in July 2010.

the *Masa* (“new dawn”) program) and to introduce routine HIV testing. The country also has a network of confidential testing centres (*Tebelopele*) throughout the country. HIV/AIDS is considered a multisectoral issue, with AIDS coordinators in every government ministry, and the National AIDS Coordinating Agency (NACA) working to link work in different sectors.

Botswana’s National Policy on HIV/AIDS, which dates to 1998, lays out the responsibilities of different government ministries with respect to the virus and includes a section on ethical and legal aspects. This section targets discrimination, describes testing protocols, addresses confidentiality, and specifies that there should be no restrictions on travel based on HIV status (Botswana Ministry of Health 1998). It contains no direct reference to rights. The country’s statutes make two direct references to HIV in law, both addressing HIV as an aggravating factor in rape and consequently increasing the length of imprisonment.

3.3.1.2.3 Civil Society Context

Although they share a common border, one respondent described the advocacy cultures in South Africa and Botswana as being “like night and day.”¹⁷ A peaceful, democratic country, with the same party in government since independence in 1966, Botswana is often described as having a “weak” (Holm et al 1996 as cited in: Somolekae 1998, 5) civil society, with some attributing this characteristic to “political and social stability” (Shale 2009, 71-72) and “a culture of non-questioning” (Mogalakwe and Subudubudi as cited in: Shale 2009, 71-72).

¹⁷ Author’s interview, Employee, International NGO, 2 July 2010, Gaborone, Botswana.

In a place that is small enough for actors in government and civil society to know each other personally, direct confrontation is occasional and generally discouraged. The country's political culture is described as being a force which "compels/constrains contestants to meet and exchange views rather than to disengage and resort to the trading of unpleasant remarks in the media and to industrial action on the street" (Maundeni 2004b, 619). Extensive and inclusive dialogue is the dominant course of action, with efforts made to invite all related parties, a process described as "mutual criticism in each other's presence" (Maundeni 2004a). One employee of an international NGO based in Botswana elaborated:

this is a very consensus-oriented society, very small society, and that both means that it's relatively easy to have a seat at the policy tables and to have sort of rational discussions about it, and it also means that at times people react very badly to the more overt forms of activism.¹⁸

He added that while South Africa is "a society that's used to tension and that's used to conflict," in contrast, Botswana "is used to agreement and concordance, a much more gentle and amenable and consensus-based decision-making process" adding "it's harder to do advocacy in Botswana."¹⁹ While government does not generally exert strong control over civil society groups, forceful criticism is uncommon and often regarded as rude or ungrateful. In a few cases, where strong critiques have been made on nationally-sensitive topics, there have been unfavourable responses on the part of both government and the public.²⁰ Strikes are unusual,²¹ and the government is the nation's largest employer. The majority of civil society groups are

¹⁸ Author's interview, Employee, International NGO, 2 July 2010, Gaborone, Botswana.

¹⁹ Author's interview, Employee, International NGO, 2 July 2010, Gaborone, Botswana.

²⁰ Examples include academic Kenneth Good's deportation allegedly over comments made related to the relocation of Kalahari San indigenous people and diamond mining, international petitions coordinated by international NGO Survival International on the same topics have resulted in unfavourable front page news coverage.

²¹ Strikes are unusual but not unheard of, in 2011 there were lengthy health and education sector strikes, for example, but this was a notable and relatively uncommon event.

engaged in service provision rather than advocacy. This theme is also evident among groups working on HIV, with groups conducting advocacy constituting a small minority of the Botswana Network of AIDS Service Organisations' membership. Only two groups listed in a directory of HIV stakeholders including human rights in their descriptions of organisational activities and mandate.

Botswana is a useful and interesting case for this study because of its exceptionally high rate of infection, high rate of government intervention, and for its small consensus-based civil society. The cross-currents of local advocacy norms and international linkages evident in Botswana are some of the key factors that this study seeks to understand with reference to rights language.

3.3.1.3 Uganda

3.3.1.3.1 HIV Context

Uganda's epidemic has been one of the world's most high profile. Uganda's prevalence rate is considered in the middle range, having fallen to 6.7% from peak prevalence rates of more than 30% in the 1980s (Uganda AIDS Commission 2012). The country was one of the first hit by the virus with the first reported case in 1982. The virus spread rapidly from the shores of Lake Victoria. Initially it was a straightforward story of devastation, with high death rates, and no treatment available. Circa 1995 ARVs became available overseas, and, with time, to a small minority of Ugandans who could afford them. This development, although generally positive, introduced a profound inequity where survival was tied to geography and income (Mugenyi 2008). ARV roll out in Uganda was finally announced in 2003 with donor support. By this time, however, Uganda was already "bask[ing] in the praise of the international community" (Kelly 2008), having been widely acclaimed for its successful interventions which had dramatically

lowered the rate of infection. Recent estimates (2011) place prevalence rates at 6.7%, indicating a slight rise in prevalence (from 6.4% in 2004/5) (Uganda AIDS Commission 2012, 1-2). There has also been a shift in the nature of the Ugandan epidemic, with married couples an emergent risk group.

HIV had a moderate level of prominence in visible messaging and media in Uganda. Billboards observed in Uganda²² fit into four campaigns²³, one focusing on the “sexual network” mapping out interactions between different people and their sexual partners (“The sexual network does not stop with you! HIV spreads like wild fire in sexual networks! To live a good life, get off the sexual network”) and the impact (“mummy is sick most of the time because of the sexual network”). A second campaign, “go RED [Reliable, Exceptional, Dependable] for fidelity” has a clear monogamy focus, a third campaign “get together, know together” focuses on couples, including those with discordant serostatus, and a final campaign focuses on prevention using the tagline “stay HIV negative, stay healthy.” These campaigns assume basic knowledge about HIV transmission and target social context, rather than immediate medical cause. Print media coverage included a variety of issues relating to HIV, including prevention initiatives, an advice column, events, and news linked to three HIV-related bills.

²² 12 posters observed in Kampala

²³ Observed in March 2010. Complete listing of primary materials available in Appendix B.

3.3.1.3.2 Government Response

Uganda has received a high level of acclaim for its interventions, widely hailed as a success story due to its dramatic reduction in prevalence rate (World Health Organisation 1997). This success is attributed to a “high level of commitment to HIV prevention and care” and “[f]rom the outset ... involv[ing] religious and traditional leaders, community groups, NGOs and all sectors of society, forging a consensus around the need to contain the escalating spread of HIV and provide care and support for those affected” (Kelly 2008). Specifically, the “zero grazing” approach which emphasised monogamy, and faith-based approaches are often highlighted as distinctive and effective Ugandan interventions. In addition to these approaches Uganda was one of the earliest to introduce innovations such as same day testing (1997).

Domestically, the government response is portrayed as multisectoral, with HIV/AIDS “declared a development and security crisis” in 2000, meaning the epidemic is addressed by the Poverty Reduction Strategy (Uganda AIDS Commission 2012b). The country employs varied interventions including media, and a think tank on AIDS. The issue is prominent across many government agencies and departments. The Uganda Human Rights Commission addresses the virus in its work and reports, identifying access to ARVs, access to condoms, denial of the right to education, discrimination, employment issues and privacy as key human rights issues relating to HIV status (Uganda Human Rights Commission 2008, 17).

At the time of interviews, there were three high profile bills which were linked directly or indirectly to HIV/AIDS. The first, the HIV/AIDS Control Bill aimed at controlling the spread of

the virus, but included a number of punitive and criminalising provisions,²⁴ the second the Counterfeit Good Bill included generic drugs as counterfeit,²⁵ and the third the Anti-Homosexuality Bill which has received a high level of international attention (Kron 2012). The latter bill, which, among other things proposes life imprisonment penalty for same-sex sexual relations, includes an “aggravated homosexuality” category, which includes having sex while HIV positive and carries the death penalty (Parliament of Uganda 2009). As of October 2012, none of these bills had passed.

3.3.1.3.3 Civil Society Context

Uganda’s civil society is described as having “moderate strength,” with significant outside assistance, with estimates of more than 25% of official aid going towards NGOs (Opoku-Mensah 2008,79). Concentrated in Kampala, civil society exists in an environment with varying relations with government, including straightforward partnerships with civil society groups conducting direct service provision, and suspicion and regulation, particularly on some sensitive topics. There are also strong differences between the post-conflict environment of Northern Uganda, and the southern part of the country which has been comparatively unaffected by the conflict.

Civil society groups have played a very significant role in combating the pandemic, providing care, testing, treatment and psycho-social support, and conducting advocacy. Indeed, the Uganda AIDS Commission notes that, “many critics of the country’s response argue that most HIV/AIDS work in Uganda has been left to CSOs [Community Service Organisations]” commenting that this is not “a weakness on the side of government but rather complimentary” as “[g]overnment

²⁴ For example criminalisation of transmission.

²⁵ The bill has since been amended, but concerns remain (See: Kagumire 2010).

policies recognise the role [of] CSOs as partners in national development priorities” (Uganda AIDS Commission 2012a). The Uganda Network of AIDS Service (UNASO) estimates that there are about 2500 Ugandan HIV organisations of which 1000 are members of UNASO.²⁶ In line with UNASO’s stated mandate to “provide coordination, representation and networking among civil society AIDS Service Organisations (ASOs) for enhanced quality HIV and AIDS service delivery” (Uganda Network of AIDS Service Organisations 2012) service delivery is the primary activity of its membership, with the organisation’s chair estimating about 25% of membership are advocacy groups. The language of rights is not unfamiliar in HIV advocacy in Uganda, but tends to be used in conjunction with other approaches, such as development, or only on specific topics, with a noted connection to gender. In contrast to Ghana and Botswana, there also is a discourse around right to health/ health rights which while not dominant, was raised by some civil society groups interviewed, as well as by government. Perspectives among civil society representative interviewed indicated a shift over time from a public health approach to a development / human rights approach as the pandemic progressed and as anti-retrovirals became more widely available. These national differences provide important variation through which to examine the puzzle of the rights frame in HIV advocacy.

3.3.1.4 Ghana

3.3.1.4.1 HIV Context

Providing a good contrast with the other cases, Ghana does not have a generalised epidemic,²⁷ with markedly higher prevalence rates in border areas, and among particular groups (migrant

²⁶ Author’s interview, Employee 1, Uganda Network of AIDS Service Organisations (UNASO), 19 March 2010, Kampala, Uganda.

²⁷ A generalised pandemic is defined as a prevalence rate of greater than 5%.

workers, sex workers, truck drivers, MSM). The country's first infections were reported in 1986, with a peak prevalence of 3.1% in 2003 (United States Agency for International Development 2012), and recent rates of 1.8% (UNAIDS 2012). The response to the pandemic has been chiefly located within the Ministry of Health's National AIDS Control Programme, which was set up in 1987, but while "initially everything was centred in the Ministry of Health"²⁸ over time with rising prevalence rates in Ghana and migration into Ghana from nearby countries with higher prevalence rates the focus became more holistic. The multi-sectoral and supra-ministerial Ghana AIDS Commission established in 2002 with the mandate to "provide support, guidance and leadership for the national response to the HIV and AIDS epidemic" (Ghana AIDS Commission 2010).

Of the countries profiled Ghana had the lowest profile in relation to HIV and the lowest prevalence rate. HIV appeared relatively rarely in the print media.²⁹ HIV related billboards³⁰ tended to depict direct messages of awareness and prevention ("AIDS spreads through sex," "HIV/AIDS is real," "You can prevent your baby from HIV/AIDS infection") often with organisation or locational ties,³¹ including duplicate billboards (one in English, one in French) located at the bus station and targeting travellers ("Traveller Never Forget: AIDS cross' (sic) borders, let's prevent it"). Methods of prevention referenced in these materials included being faithful to an uninfected person (1 billboard), condom use (3 billboards) and abstinence (1

²⁸ Author's interview, Sam Antimadu-Amaning, Ghanet, 9 February 2010, Accra, Ghana.

²⁹ Based a one month daily survey in February 2010 of the *Daily Graphic*.

³⁰ 9 billboards were observed in Accra, 1 in Tema and 1 in Tamale. All observed in February 2010. Billboards are listed in Appendix B.

³¹ For example: "HIV/AIDS is preventable just as fire is" in front of the fire brigade, "Officer! Know Thy Status" in front of customs, "Live to Enjoy Water: Know Your HIV/TB Status today" in connection with water affairs.

billboard). Four targeted particular constituencies (women, mothers, travellers (2 billboards), customs officers).

3.3.1.4.2 Government Response

The National HIV/AIDS and STI policy is quite explicit in its reference to rights, with 15 references, and, a statement of the policy's guiding principles for the policy noted that the policy is "[d]erived from the recognition that adequate healthcare is an inalienable right of every Ghanaian including those infected with HIV or other STIs" (Ghana AIDS Commission 2004, 2.0). There is reference to international human rights instruments, including the ICESCR and the African Charter on Human and People's Rights, the "highest attainable standard of health" and the importance of "ensur[ing] that the basic human rights of every person in Ghana, especially persons infected with HIV or AIDS, are respected, protected and upheld" (Ghana AIDS Commission 2004, 2.6).

Government interventions are viewed to have been effective, particularly in high prevalence areas, but there is a lack of data and "implementation clarity" regarding implementing agencies (Fobril and Soyiri 2006, 464). Fobril and Soyiri argue that while there is "strong political will...political commitment has remained very low," viewing the "large gap" between the two as a "major setback to efforts to lower prevalence" (Fobril and Soyiri 2006, 458). They note:

The involvement of politicians in the fight against the disease has remained at rhetoric level, thus reducing momentum in the allocation of adequate money to support AIDS control activities. The central government has focused largely on developing policy strategies but has ceded funding of activities relating to the policies to external donors (Fobril and Soyiri 2006, 458).

The role of external donors was also with respect to civil society intervention, with one respondent commenting that early initiatives were, “pushed by the foreign and international NGOs and the development partners until lately the local NGOs got themselves involved.”³² Fobril and Soyiri argue that “the majority of the activities on HIV/AIDS in Ghana appear to be donor driven, usually with funding from bilateral and multilateral agencies” (Fobril and Soyiri 2006, 461). Learning across borders was also emphasised, with the push to increase action on HIV influenced by rising prevalence rates in neighbouring countries, and learning from how other regions and countries harder hit were dealing with the pandemic, “especially Eastern African countries.”³³

3.3.1.4.3 Civil Society Context

The role of NGOs with reference to HIV in Ghana is described as “largely ... advocacy, health education and support for those with the disease” (Fobril and Soyiri 2006:462) and “educating the populace and sensitising them on the realities, risks and dangers of HIV/AIDS, distributing condoms and HIV/AIDS drugs to the youth, adults and the needy in society” (Mills 2007). In an analysis of actual and potential NGO action on the topic, one commentator made a comparison to TAC and noted, “it is hoped that NGOs in Ghana will be more active in the battle against the disease not only from the social and medical fronts but also from the legal front” (Mills 2007). As in other jurisdictions outside of South Africa, confrontational advocacy was not looked on positively, with the head of Ghanet noting that in terms of advocacy strategies, “what we have not done is go on the streets” commenting that this “might work but [also] might give you a bad

³² Author’s interview, Sam Antimadu-Amaning, Ghanet, 9 February 2010, Accra, Ghana.

³³ Author’s interview, Sam Antimadu-Amaning, Ghanet, 9 February 2010, Accra, Ghana.

name.”³⁴ Instead, they relied on “jaw type” advocacy, defined as “talk, talk, talk and talk,” noting, “we are always there dialoguing” with government.³⁵ There was no obvious preference of frames, with care and support overall seeming to be dominant themes and areas of work, providing good variation on this key analytical dimension of my study.

Among the groups I spoke with, I encountered frames of gender, gender and rights (Society of Women and AIDS, Ghana), peace (Centre of Awareness), religion (Dawah Academy), gender, poverty and rights (Enterprise for Women in Development), gender and reproductive health (SCAN), human rights advocacy (Human Rights Advocacy Centre). There are relatively few organisations for whom advocacy is their primary activity. In the sector prevention is a focus, and among support groups treatment, care and support are priorities. Where advocacy exists the most common areas of work were on access to treatment (specifically wanting anti-retroviral therapy to be free), and work against stigma and discrimination. Generally there is little “activist” inclination and more emphasis towards dialogue and using sympathy and education as advocacy strategies. In contrast with other places, there was a high level of integration of work on HIV with other health issues in Ghana (for example combined HIV and TB posters and programs, HIV and reproductive health was particularly popular- with several mentions of a donor push for integration, offices of organisations working on HIV have posters up about malaria and maternal mortality rates).

³⁴ Author’s interview, Sam Antimadu-Amaning, Ghanet, 9 February 2010, Accra, Ghana.

³⁵ Author’s interview, Sam Antimadu-Amaning, Ghanet, 9 February 2010, Accra, Ghana.

3.3.2 Selection of Organisations

The same logics of control and difference described above are applied to civil society organisations which are selected from within the countries outlined above. The “universe of cases” (Munck 2004, 3) consists of civil society organisations in sub-Saharan Africa working on HIV who conduct advocacy. So as to compare organisations that have some similarity and to control for influencing factors, groups were selected that are based in Africa, as opposed to international groups running programs on the continent. In order to increase breadth and allow for the possibility of generalisation across this group, both groups structured as networks and those that were not were identified; groups with varying substantive foci within the topic area and different levels of international interaction were chosen. Organisations operating at the local, national and regional level were also selected, including two groups that operate regionally in Southern Africa. Cases were selected with variation on the dependent variable (the use of the human rights frame), with cases chosen that both use and do not use this frame as their primary organising principle.³⁶ The human rights frame is understood as a continuous rather than a binary variable (Munck 2004, 3), with cases selected with variation in the extent of use (from no use at all, to extensive use).

3.3.3 Categorisation of Organisations³⁷

Organisations were selected with variation on the dependent variable, which is to say groups were deliberately identified who relied primarily, somewhat and, very little (or not at all) on the rights frame. This initial selection was made prior to fieldwork and, as such, categorisation-based

³⁶ Cases were chosen based on the researcher’s knowledge of the field and in consultation with individuals who have or are currently working with organisations in this field in other parts of Africa. An internet search for organisations (including databases of network members at national and continental level) was also undertaken.

³⁷ A detailed explanation and tabulation of the categories discussed in this section is available in Appendix A.

selection was made according to existing knowledge, analysis of the organisational mandate and documents, and field-based recommendations. While it was clear, even at this juncture, that classification would involve nuanced shades of grey with discrepancies between written and oral records, between publications and activities and between different personal accounts, these complexities intensified once in the field. Organisations did not always fall in the categories that they were expected to at the outset, as organisational mandates did not always coincide with realities on the ground that sometimes shifted with time and changes in leadership. The process of analysis allowed for more specific placement of organisations along the spectrum between dominant and non-use of rights language, with some movement from their anticipated pre-fieldwork classification and their final location.

Analysis with regards to classification included examining a variety of pieces of evidence from each group in order to determine the prominence given to human rights language within the organisation and its role in advocacy. Cases are examined with reference to five measures: (1) rights in purpose, (2) rights in print and rights on display, (3) rights in action, (4) rights in context and time, and, (5) rights in speech. Each measure is scored out of twenty. For the purpose of this level of analysis the use of rights language was taken at face value: whether or not the word ‘rights’ appeared in the sources being examined. There was no sorting out of, for example, the use of rights language with reference to non-codified concepts,³⁸ as the borrowing of rights language in such contexts still constitutes ‘rights language.’ Similarly, respondents were

³⁸ For example, in previous work I had frequently encountered reference to “the right to sex” which, strictly speaking does not exist in any human rights convention that I am aware of.

not asked to ‘source’ their rights by reference to domestic or international instruments. This ‘open’ selection allowed me, in the larger case analysis component, to examine the meaning and application of rights language and not to have cases standardised around a particular understanding of this discourse.

Rights in purpose is based on the inclusion of rights in the organisation’s mandate or objectives (/10) and reference to rights by interview respondents when describing the organisation’s work (/10). Rights in print and rights on display includes the frequency of rights references in organisational documents (/10) and the prominence of rights in materials displayed in organisational offices (/10). Rights in action examines the use of rights in campaign messages, examining whether rights are the dominant frame in campaigns over time (/10) and whether one or more current campaign invokes rights as the primary frame (/10). Rights in context and time examines consistency over time (/10) and setting (ie local, national and international, or head and regional office) (/10). Rights in speech examines the frequency of rights references by respondents in interviews (/10) and whether rights references are unsolicited (/10). Scores from the measures outlined above are tabulated in the chart below. These scores indicate rough evaluations useful for the purpose of classifying these organisations into groups with regards to the use of the rights frame. While not statistically significant, the notable breaks in scores indicate meaningful variation in the use of the rights between the organisations studied.

Table 1: Scoring Rights Use by Organisation

Organisation	Rights in purpose (/20)	Rights in print and rights on display (/20)	Rights in action (/20)	Rights in context and time (/20)	Rights in speech (/20)	Total (100)
BONELA	17	20	20	20	20	97
ARASA	15	15	20	20	18	88
TAC	16	10	20	20	16	82
NACWOLA	8	10	10	10	16	54

SAfAIDS	7	10	10	10	16	53
TASO	9	10	0	10	12	41
NAP+	7	0	0	10	8	25
WUAAG	2	5	0	0	10	17
Kuru	0	0	0	0	0	0

The purpose of this system of classification is to disaggregate and group the organisations into three subsets fitting a general profile from which internal and cross-subset comparison could take place. The organisations were separated into these categories based on natural break points in the data. Rights dominant, the first subset, includes groups which have a clear emphasis on rights in at least some key organisational documents, where the majority of respondents identify rights as the group's main approach and may identify the group as a human rights organisation and themselves as human rights activists within it. Multiple campaigns have been carried out in which the primary message is one which directly references and highlights rights. Minimal variation is noted between different staff positions or offices, between different contexts (for example communication with donors versus communities, domestic versus international) and, where data is available, similar consistency is visible over time. The rights limited category includes organisations where rights were not referenced in organisational documents and respondents did not refer to rights when describing the organisation and its objectives, and few if any campaigns feature rights. Groups in the rights mixed category fall somewhere in the middle. These organisations have inconsistent or selective use of rights, using the frame in some contexts, at some levels of the organisation, or on some topics and at some times. This includes groups where the framing of each campaign is unique and responsive to particular points of leverage.

Table 2: Categorising Organisations by Rights Use

Rights Dominant	Rights Mixed	Rights Limited
BONELA ARASA	NACWOLA SAfAIDS	NAP+ WUAAG

TAC	TASO	Kuru
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3.3.4 Selection of Participants³⁹

Participants within each organisation were selected with an aim of having representation across different types of employees,⁴⁰ including in different locations where organisations have more than one office. Employees who had no involvement with advocacy campaigns or related activities were not interviewed. All interviews were voluntary and, as such, there was also an element of self-selection. While the number of direct refusals was minimal (2), there were likely indirect or passive refusals, in the form of people not getting back to me regarding inquiries, or scheduling conflicts.

3.4 Operationalisation: Data Gathering and Analysis

This research is primarily fieldwork based, drawing heavily on semi-structured interviews, as well as document analysis and naturalistic observation. Field work was carried out in Switzerland (Geneva) and Kenya (Nairobi) in November 2009, in Ghana (Accra, Tamale, Cape Coast, Koforidua) in January and February 2010, Uganda (Kampala) in March 2010, in Botswana (Gaborone, D'Kar, Ghanzi, Mochudi) in June-July 2010 and June 2011, and South Africa (Cape Town, Durban, Pretoria, Greater Johannesburg) in July - August 2010 and June 2011. Two interviews were conducted in the United Kingdom (Colchester, Brighton) in January and May 2010 respectively, and one during the World AIDS Conference in Austria (Vienna) in July 2010. While in Ghana, I was a Visiting Researcher with the Kofi Annan International Peacekeeping Training Centre's Research Department. In Botswana I was affiliated with the University of Botswana's Schapera Institute and supervised by Professor Treasa Galvin.

³⁹ A complete list of those interviewed is available in Appendix A.

⁴⁰ The word employee here is used broadly to include anyone who carries out key functions of an organisation regardless of their payment, as such it includes some volunteers and members.

The methodological structure of this study is driven by three objectives drawn from the hypotheses outlined earlier. These objectives are: 1) to gain an in-depth understanding of the factors driving the choice of frame within each of the case studies, 2) to gain an understanding of the context in which these groups are operating, 3) to carry out a structured comparison among the cases.

3.4.1 Towards Objective 1): Factors Driving the Choice of Frame

As this is primarily a project of theory development, the purpose of the investigation is to locate the critical variable(s) that lead to the selection or non-selection of the rights frame. As noted earlier, this includes both variables identified deductively prior to field research and variables which emerged inductively during fieldwork. Because of the multiple dynamics at play and the possibility of the use of different frames in different contexts (for example in small communities vs. in relation to funders, etc.), it was necessary to use a variety of approaches. Semi-structured interviews with organisational staff formed the primary data source for most cases studies, with interviews carried out with former staff and particularly founders, where possible. Naturalistic observation was undertaken where practicable within organisations with a particular emphasis on displayed materials, training, advocacy campaigns and events. Organisational materials such as posters, pamphlets, stickers, t-shirts, press releases, newsletters, websites, annual reports, etc. were analysed as was press coverage where available, as well as external perception of the group (through interviews in the sector, including donors). Within each organisation, I made an effort to identify domestic and international linkages (for example with funders and international coalitions, as well as with domestic NGOs and government) and followed up with research with these groups and interviews where practicable. Towards this objective sequencing, chronology,

triangulation and process-tracing were critical in separating different possible variables and in comparing and verifying accounts of events.

3.4.2 Towards Objective 2): Understanding Context

In order to gain an understanding of the context of both global and domestic discourse, a series of contextual interviews were carried out in Ghana, Uganda, Botswana and South Africa, as well as with affiliates of international organisations in the United Kingdom, Switzerland, Kenya and Namibia. Interviews were carried out primarily with programme personnel within UNAIDS, a UN agency that often has a high level of engagement with the NGO sector, as well as with other related agencies including the WHO, UNFPA, and UNHCHR, the Former Special Rapporteur on the Right to Health, and the Southern African Development Community (SADC) Parliamentary Forum. In each country, I aimed to conduct interviews with a broad cross-section of NGOs working on HIV/AIDS and to obtain directories of such groups (where they existed) in order to gain an understanding of the national sector as a whole and be better able to situate my cases within this context. A brief review of activist history and contemporary implications of rights language in each country was also undertaken, which involved discussion with academics, reviewing country-specific academic literature and following leads raised in interviews. I also interviewed personnel within government in each of the countries hosting case studies. This primarily involved interviewing personnel within the Ministry of Health regarding their perspective on human rights in relation to the pandemic, and their interactions and perceptions with NGOs working in this sector. Additionally I conducted a print media survey (one major print publication per country, for one month), naturalistic observation of key events, and a survey of public messaging around HIV (principally billboards), and of posters and displayed materials in the locations where I conducted interviews.

3.4.3 Towards Objective 3): Comparing Among Cases

While the variables identified through the hypotheses were investigated through in-depth analysis of cases, these data are also utilised as a form of structured comparison between the cases in order to identify common or divergent trends.

3.4.4 Observable Implications

Chapter 2 identified ten possible hypotheses drawing on the literature, as well as previous experience in the field and ideas that emerged through the process of fieldwork. Because a choice is an internal, unobservable practice, observable implications were brainstormed for each hypothesis to identify processes, actions and statements that can be witnessed to confirm or refute various potential explanations. These observable implications serve to translate hypotheses into operationalisable research techniques through which to structure field research. The observable implications also address the three objectives described above and facilitate consistent comparison across cases. Observable implications are identified here in relation to each of the ten hypotheses and are divided into three categories: (1) intra-organisational factors, (2) extra-organisational factors and (3) factors relating to impact.

3.4.4.1 Intra-Organisational Factors

H1: Organisations that choose rights as a primary frame do so because personnel (particularly leaders) hold a strong personal belief in human rights and have an expansive understanding of human rights as a mega-frame that includes most or all of the topics on which the organisation conducts advocacy.

Observable Implications:

- Leaders have a strong rights orientation and rights background prior to involvement with the organisation as evidenced by education or previous employment

- Personnel express a strong belief in rights in interviews, and in documents such as newsletters or media interviews
- Groups use human rights language consistently despite changes in funding patterns or priorities
- There is a noticeable presence of human rights language within staff meetings and internal discourse
- Documentation indicates that personnel hold a personal belief in rights over time (for example pre-dating involvement with the organisation, after leaving the organisation, throughout periods of relative unpopularity)
- Groups continue to use the frame despite noticeable setbacks and indications that an alternative approach might be more successful
- Groups continue to use the frame despite its lack of resonance in the local context, or consistent feedback about its inappropriateness (for example newspaper articles about human rights being a culturally foreign concept, community feedback during events, information given in interviews on obstacles encountered)
- Continued use of the frame despite lack of evidence of its effectiveness at mobilising (or evidence of its negative effect)
- Rights are reported in interviews as a broad concept, with a wide range of topics considered to fall within the rights frame. Campaigns on a wide range of issues use the rights frame.

H2: Organisations that choose rights as a primary frame do so because they have a centralised structure (secretariat – based) which allows for regular interaction with rights-oriented leadership and the development of a rights-based organisational culture.

Observable Implications:

- Organisations with rights as a primary frame have a centralised structure with a single head office
- The office is a central place of work, as opposed to primarily providing field support and personnel work primarily from the office rather than remotely
- Personnel have frequent interaction with leadership within the office as evidenced through observation and interview commentary
- Leadership have expressed rights orientations as evidenced through interview responses, organisational documents such as newsletters and press accounts
- Personnel refer to leadership as having a strong rights orientation in interviews
- Non-leadership personnel report acquiring rights orientation after joining the organisation
- In interviews personnel report rights-oriented conversations in the workplace, in both formal meetings and informal settings (i.e. over lunch)

H3: Organisations that choose rights as a primary frame do so because they were established with a rights oriented mandate establishing a trajectory of path dependence.

Observable Implications:

- Organisational mandate at the time of founding gives prominence to rights

- Organisational mandate maintains rights focus over time
- Organisational activities as evidenced through newsletters, campaign messaging and press releases reflect the organisational mandate
- In interviews, respondents, particularly those with a lengthy history with the organisation, attribute rights orientation to the group's initial mandate
- Leadership and personnel were recruited after the mandate was established and in line with its provisions
- Explanations of organisational identity in interviews, press accounts and other documents reflect the group's mandate

3.4.4.2 Extra-Organisational Factors

H4: Organisations choosing rights as a dominant frame do so because they exist in environments where rights discourse is prominent domestically, and adopt it through a process of socialisation. Employing rights enables them to speak a common local language of advocacy that is readily understood.

Observable Implications:

- There is a pre-existing rights frame within the country in use in relation to health or in other sectors that is a dominant, culturally or historically-grounded frame. This is evidenced through:
 - Use of rights language by government leaders in public statements and media reports
 - Use of rights in public messaging by government (ie public health campaigns, electoral campaigns, public safety, education)
 - A large number of rights-based civil society groups
 - Prominence of rights language in media
 - Historical movements that employed the language of rights
 - Rights-based alliances or networks of civil society groups
 - Rights terminology in local languages and related local concepts
 - Use of rights in business or advertising
- In interviews rights are not described as foreign concepts but as locally used and understood.
- NGO leaders and/or membership are socialised domestically by rights-language prior to involvement with the organisation
 - Personnel have previous employment in rights-oriented positions within the country
 - Personnel have education that includes rights training within the country
 - Personnel report familiarity with rights prior to employment
- Groups belong to networks or alliances of civil society groups in which rights is a dominant or prominent discourse

H5: Organisations choosing rights as a dominant frame do so because they are closely and regularly linked to international groups that employ rights and through repeated interaction adopt

rights language through a process of socialisation. Employing rights enables them to speak a common language with their international allies.

Observable Implications:

- Rights-language is the dominant contemporary frame in this field among advocacy organisations
- Groups with international exposure (internet connections, exposure to international media, communication with international groups, participation in international conferences, hosting international cooperants, volunteers or consultants) are more likely to use the rights-frame than those that do not
- Evidence of interaction with groups using the rights frame prior to its adoption (for example attendance at international conferences, meeting with domestic groups using this frame, membership in networks using this frame, correspondence with groups falling in these categories)
- There is an increase in rights-language (or its adoption) following participation in international conferences, or membership in regional or international networks where this frame is dominant
- Personnel report adopting the rights frame due to international connections
- Organisations are involved in international networks where rights is the dominant frame

H6: Organisations that choose rights as a primary frame do so because it allows them a unique niche relative to other organisations.

Observable Implications:

- Strategic planning documents, reports by internal or external consultants include an analysis of the NGO sector in that NGO's target area, and make explicit note of competitiveness and the need to expand into health rights for this reason.
- Membership-based organisations have documented pressures from membership (statements at AGMs, reports from regional branches) for expanded work in the area of health rights and documented competition for membership from other groups already working in this area.
- NGOs make the shift towards a rights based approach to health despite the absence of evidence supporting other hypotheses, and where there is some evidence, or an expressed belief that this shift will increase the organisation's competitiveness
- NGOs who have taken up the rights based approach receive greater media coverage than those who do not
- There is some evidence of organisational decline (lowered profile, decreasing membership, difficulty acquiring funds, lowered perceptions of legitimacy) or death of groups that have not made this transition.
- There is some evidence of organisational success, expansion and out-competing by organisations who make the transition to a rights-based approach (or begin with it). This includes surpassing older, more established NGOs, having greater membership expansion, being requested to represent the sector to national and international bodies where consultation with that sector is considered important (ie participation in UN treaty

bodies, to national shadow reports, to national consultations), and having greater longevity.

H7: Organisations who choose rights as a dominant frame do so because they have persuasive donors who prefer, promote and encourage this frame providing funding for activities that are congruent with it. Groups choose this frame in order to secure and maintain funding.

Observable Implications:

- The adoption of the rights frame by the organisation follows the adoption of a rights frame by major funders
- There is evidence of communication of the organisation with funders adopting the rights frame prior to the adoption of such a frame
- Funding guidelines of relevant funding organisations use rights language in their call for funding proposals
- The organisation uses different frames and different ideological approaches in different funding proposals
- Internal (memos, internal email, meeting minutes, oral communication) and external (press releases, events, campaigns) reflect differences in the prominence, legitimacy or appropriateness of the rights approach
- Documents intended for donors or for an audience outside of the country use rights-language while those used within the country do not, or give it a lower profile.
- Documents, posters and other materials highlighting a rights approach are not widely distributed and remain in storage.
- Groups that use a rights frame receive or are perceived to receive more funding than those that do not.
- Strategic planning within individual organisations or NGO coalitions identify funding shifts and trends towards human rights language
- There is an increase in the number of organisations with a human-rights focus, human rights in the organisation name, human rights in job or project titles in concert with an increase in funding guidelines highlighting human rights.
- Over time increases as above continue despite no evidence of a belief in the rights frame, or evidence of increased effectiveness, but in the presence of increased funding.

3.4.4.3 Factors Relating to Impact

H8: Organisations using rights as a dominant frame do so because they believe that rights have a distinct and empowering impact on the target groups with whom they interact, enabling them to better claim health care services and transforming the nature of their relationship with the state from one of a passive recipient to one of an active citizen.

Observable Implications:

- Respondents list empowerment as a key outcome of a rights-based approach and recount stories of changed interaction with health care services

- Organisations materials portray rights as changing interaction with health care services and depict an empowered interaction (ie “you have the right to demand X at the clinic”)
- Respondents describe this outcome as unique to and different from the impact of other frames
- This impact is not reported in relation to other frames, or by groups who employ other frames

H9: Organisations using rights as a dominant frame do so because they believe that the approach will be successful in mobilising supporters and they anticipate that such mobilisation will effect policy change.

Observable Implications:

- Groups using a rights-frame have a higher visible presence in the form of: attendance in street demonstrations, protests, media coverage than those who do not
- Turn out to events framed in rights-language is larger than those that are not framed in rights-terms
- There is a higher level of engagement with rights-based campaigns, as evidenced by leadership roles being taken on by a larger number of people, events being initiated from outside of the organisation’s central office, letters to the editor written by membership
- There is a higher level of willingness among supporters and membership to donate time (such as weekend or evening events for which there is no, or insignificant individual material benefit), skills (such as the development or carrying out of training), and goods-in-kind (such as food, meeting space, etc.)
- Increased levels of mobilisation (as evidenced by membership base, turn out at events and rallies) at rights-based events/campaigns
- Government is reported to respond to public mobilisation (statements by government, actions by government, statements by NGOs)
- NGOs report in interviews and organisational documents that rights are successful in mobilising supporters and/or report this as a motivator for frame use

H10: Organisations choosing rights as a dominant frame do so because they anticipate government will respond to rights based claims. They expect that rights-based campaigns will lead to changes in law and policy.

Observable Implications:

- Internal documents (memos, minutes of meetings, strategic plans, SWOT⁴¹ analyses) indicate campaigns with the identified goal of influencing decision makers and the strategy described as one based on rights-language.
- Rights campaigns are carried out publicly with the stated goal of influencing government or other decision-makers.

⁴¹ Identification of: Strengths, Weaknesses, Opportunities and Threats - a common strategic planning tool.

- Present campaigns are modeled on past campaigns by the same or other organisations which used the rights-frame and was seen as having a successful outcome in influencing decision-makers
- Reference is made to the success of past campaigns using a rights-approach within the organisation and the organisation is planning a campaign using a rights-frame
- There is evidence of successful campaigns based on rights-claims and unsuccessful campaigns based on other claims
- Statements are made by NGO leaders and supporters in the press and public about being successful in rights-based campaigns
- Statements are made internally within organisations about the belief that a rights-based approach will be effective
- Use of rights language is consistent across all levels and contexts of the organisation's work (ie internal grassroots, donor interaction, international, interaction with governments)

These observable implications were used as a base from which to generate a list of possible sources that could contain information that would confirm or refute hypotheses, or suggest others. These sources include organisational documents such as annual reports, press releases, posters, march slogans, photos of events, media coverage, promotional materials, as well as 'live' sources including naturalistic observation of events such as domestic and international conference participation, meetings, training workshops, staff meetings, etc. Finally, an interview guide for semi-structured qualitative interviews was created, using the hypotheses and their related observable implications as a skeleton, but allowing for flexibility including emerging hypotheses in the field.⁴² In structuring research, attention was paid to the potential for triangulation – i.e. seeking out various sources and settings for any given claim. In terms of sources this included interviews with current, and in some cases past staff (such as founders), as well as with donors, government and UN officials. With regards to settings, attention was paid to

⁴² The interview guide is attached in Appendix A.

the language used by organisations in grassroots, office, national, media and regional or international settings.

3.4.5 Mechanisms of Analysis

Based on hypotheses outlined above, a series of inductive and deductive codes were developed in order to sort interview data more systematically. Interview data was sorted by codes, in order to identify key themes for each organisation. This information was compared with other sources of data (posters, website, presentations, naturalistic observation) in order to assess variation. Case study data was grouped into five categories: 1) Organisational Background, 2) Classification With Regards to Rights Use 3) Intra-Organisational Factors Affecting Rights Use or Non Use, 4) Extra-Organisational Factors Affecting Rights Use or Non-Use, and 5) Impact.

Table 3: Data Sources and Analysis

Section	Data Sources and Analysis
Organisational Background	Interviews, particularly with organisational founders and early employees Annual Reports History sections of websites and pamphlets Newsletters
Classification	Organisational Mandate/Objectives Frequency of Rights Reference in documents such as Newsletters (word count) Description of Organisation in Interviews Rights reference in materials displayed (ie posters, divided into organisationally produced and non-organisationally produced) Description of the Organisation's mandate from outside Analysis of rights references over time Analysis of rights references in different contexts (naturalistic observation, analysis of documents) Observation of use of rights language at events
Intra-Organisational Factors	Interview responses relating to personal beliefs on rights Interview responses relating to education and professional background relating to rights Interview responses relating to organisational niche positioning and 'branding' in relation to other groups
Extra-Organisational Factors	Record of donors (from interviews, annual reports, organisational documents)

	Focus and articulated mission of donors Analysis of focus and donors over time
Impact	Comments made in interviews about perceived impact Comments made in interviews about perceptions of decision makers Comments made by decision-makers in interviews Descriptions of campaigns (interviews) triangulated where possible with press accounts, press releases, organisational campaign materials, comments about the campaign by decision makers Observation of campaign events (where possible) Documentary evidence about policy challenges, news clippings about changes in attitudes or practices, policies? etc.

Within the impact category one or two campaigns per organisation were analysed using process tracing, a detailed compiling of information from different sources in order to piece together the story of each campaign over time, by triangulating and sequencing. Following analysis at a case level, cases were grouped according to classification on rights use, and a structured comparison was carried out: 1) between cases in each category, 2) between categories, and 3) by country/region.

3.4.6 Research Limitations, Scope Conditions and Generalisability

3.4.6.1 Case Selection

Inevitably, this study cannot have the depth of an individual case study with more extensive fieldwork, nor of a large-N study including all countries in the continent (or the world). As a theory-building project, however, the middle ground is a logical place to start as it allows for: 1) a clarification of concepts and an understanding of on-the-ground advocacy techniques and, 2) enough cases and countries to be able to begin to identify themes and persistent points of contrast and similarity.

As a small N study, this project aims to provide selected snapshots of the topic at hand – enough to give a sense of the larger whole, but by no means capturing everything. At the case level, attempts were made to include a diversity of organisations within the specified parameters. In most countries for logistical reasons few interviews were carried out outside of the capital or major city and most organisations selected were based in capital or major cities. While in most countries the capital or largest city is the focus of NGO activity, it does slant selection towards larger organisations and organisations working on a national rather than local scale. Despite some efforts to include religious-based organisations, this is a group that is absent from the case studies.⁴³ While this omission was not intentional, it does allow for this factor to be held constant. At the level of individual participants efforts were made to select individuals with varying types and levels of interaction with advocacy and with varying points of view. However, as participation was voluntary, it is possible that, individuals who favour rights may have been more likely to agree (or those who hold a strong opinion in either direction on the topic) or those with whom I have a previous acquaintance or relationship. While only two respondents indicated directly they did not wish to participate in interviews, it is likely more that passive methods of refusal, such as simply not replying to the letter of initial inquiry or, perhaps, indicating scheduling difficulties were used.

⁴³ Efforts were made to contact and include groups with a religious orientation, particularly in Ghana and Botswana. In Ghana, I was unsuccessful in contacting groups with a religious frame in the Greater Accra area, but did conduct one interview with a religiously-oriented group in Tamale. However, this single interview, while fascinating, did not provide enough depth to develop a case study. In Botswana, repeated efforts were made to include a network organisation with a Christian frame, and one interview was carried out with a former staff member. A combination of illness and travel plans on the part of the potential interviewees did not make additional interviews with current employees possible.

3.4.6.2 Data Consistency

As with all methodological techniques, interviews are neither foolproof nor straightforward. The information gathered is inherently complex, fluid and subjective. People's views may shift from day to day and their expression of them often varies by context, including according to who is doing the interviewing. Interview content and depth may be affected by mood, time of day, work schedule, previous interaction, gender, or perceptions about the other person (for both the interviewee and interviewer). Interviews are nuanced communication interactions where individuals respond to subtle cues both verbal and non-verbal as well as setting, clothing, vocabulary and intonation. As an example, in one instance I unexpectedly gained respect for having walked to an interview from a village 3km away. This may have had an impact on the lengthy and fruitful interview that followed, along with a meal. On another occasion, when I unconsciously cracked my neck during an interview, in the process jerking my head slightly to one side, the person I was interviewing mirrored the action. He then responded as though I had expressed doubt or surprise in relation to what he had just said, elaborating on his last comments as a result. Due to these and other factors discussed below, the depth and quality of interviews varies. This variation, however, except where it related to the researcher's country or organisational knowledge, is not systematic.

Due to organisational realities, there is also considerable variation in the volume and type of materials available from organisation to organisation. While some organisations have volumes of publications, and extensive websites with records of newsletters spanning years, others have a single pamphlet. As most NGOs in this field do not have staff tasked with record keeping, even those with more extensive materials may have an incomplete set of annual reports, misdated or undated materials, websites that have not been updated, or several websites from different time

periods which are not thoroughly linked or indexed. The result of the variation in the existence and availability of materials is that groups with more materials could be analysed more systematically and allowed for better triangulation, while those with fewer materials were more interview dependent. Missing documents, while unfortunate and limiting the materials that could be examined, did not introduce systematic bias.

While generally clearly perceived as an outsider, I had a greater level of *entrée* in some settings than others.⁴⁴ Having spent two years as a researcher with the Botswana Network on Ethics, Law and HIV/AIDS (BONELA) in Gaborone, Botswana, I had a greater level of familiarity and knowledge of this case than of others. Within this organisation I was greeted variously as a friend, a former colleague, or as an introduced insider – to those who had joined the organisation since I had left. With some other organisations in Botswana, and Southern Africa, I had previous working relationships or encountered people who knew of BONELA and perceived me as more credible or knowledgeable as a result. In Ghana and Uganda, this experience sometimes granted me a perceived level of knowledge about HIV, NGOs, or Africa, while in other cases, it was simply too far away to be relevant. In many instances I came to organisations or individuals through a recommendation or referral, which also carried with it perceptions of legitimacy or expertise, which, depending on my level of knowledge of the referrer I may not have fully understood. Other factors including local knowledge, the ability to greet in local languages, scientific/medical knowledge of HIV and relevant treatments, knowledge of specific individuals and conferences also variously opened or closed doors. While many of these factors had an

⁴⁴ The insider/outsider divide and its implications are not always straight forward. In some cases respondents are more comfortable with an 'outsider' as there are fewer perceived risks their comments being repeated to people within their work or social circles.

element of randomness to them, my richer, deeper and more lengthy experience in some countries and with some organisations is reflected in the final product. While my specific knowledge and the way I was perceived varied from country to country, organisation to organisation and even individual to individual, I was also a constant as I conducted all interviews myself.

As the consent form signed before interviews indicated that this project focused on rights, and I asked questions in this area, it is reasonable to assume that the emphasis on rights might be over-emphasised in interviews, and that groups that do not rely on this language may in some cases claim to. In order to control for this factor I noted whether rights were referenced spontaneously or only in relation to direct questions, examined frequency and depth of responses, and triangulated with other materials (ie press releases, observation of events, newsletters, etc.).

3.4.6.3 Attribution

Any investigation of ideas and beliefs faces the challenge of correlating perceptions and intuitions with observable evidence. In examining why organisations and the individuals within them choose the rights frame, there are challenges of attribution, particularly in relation to the question of impact. Respondents may employ the rights frame because of beliefs about the impact of this frame, at an individual level, community level, or at the level of changing national policy. Each of these presents particular problems of attribution. Beliefs about individual level impact may be a strong motivator for the use of the frame. In some instances, respondents may reflect on the impact of the frame on their own self concept, and they may themselves be part of the target group. In these instances there is some direct self-reflective evidence on personal

experiences of the impact of the human rights frame. Where respondents describe the impact of the frame on other individuals, such information is harder to substantiate without a much larger interview pool, and the tracing of contacts. Perceptions of the impact of the rights frame as a mobilising tool can be substantiated by comparison with non-rights based campaigns, where similar enough campaigns exist. Nonetheless, understanding why people respond to some campaigns and not others requires data from those participating and responding as well as those initiating. Impact on a legal, policy or government practice level is particularly complex to assess. First, such change is often quite slow, meaning it may take years to show effect. Second, there may be measurable impact (for example increased dialogue on a topic, press coverage, change in societal perceptions) but not the desired outcome (legal change). Third, the desired change may occur, but there may be multiple actors who have conducted advocacy to that end, making it difficult to attribute the result to one group. Finally, even if the group studied is the only actor in a particular sector, it may be difficult to attribute success to the particular framing of a campaign. Some of these issues are substantially easier to address in some contexts than others. For example, in some contexts government may recognise the work of particular groups, whereas in others giving civil society credit is unusual. In some contexts there are also far fewer actors than others, making it easier to link activity and impact.

In each of these situations, efforts were made to triangulate, drawing on available sources of data to ascertain the extent to which ideas and beliefs communicated were reflected more broadly. As discussed, there are a number of data limitations making the extent to which this was possible variable. Nonetheless, it is important to recognise that perceptions of impact alone offer significant and useful data in explaining the choice to use the rights frame. Ideas themselves are powerful, and provide insight into frame selection and beliefs about the impact of these frames.

3.4.6.4 Scope Conditions and Generalisability

Although each case represents only itself, with nine cases, this study is large enough for themes to emerge which may be able to provide insight into the larger sector. This larger universe of cases includes the civil society HIV sector in the four countries studied (Botswana, South Africa, Uganda, Ghana) as well regional organisations in the same sector in the Southern African region. A broader and more tentative field of generalisation includes organisations in the same sector in middle-income Anglophone Africa in settings where civil society has relative freedom to operate (for example, in countries ranked as ‘free’ or ‘partly free’ by Freedom House). Generalisations at this level would be expected to be more cautious and less specific than those in the particular settings studied and would need to be verified by a larger N study. The application of findings from this study to advocacy on other health issues, in settings of conflict or recent post-conflict, in settings of greater restriction on the NGO sector, less political freedom and in situations of greater deprivation would need to be undertaken cautiously and understood as the testing of theory in a new setting. Similarly, given the emphasis of this study on language use, the extension of these findings to francophone, lusophone or Arabic regions of Africa would require further study. As a project of theory construction this project entails the first foray into a new area of study. Consequently, there are many possible steps to follow including testing, refining and exploring the applicability of the explanation developed to new topic areas and to contexts beyond the African continent.

Chapter 4: Rights as a Dominant Frame

This chapter examines three organisations that employ rights as a dominant organisational frame. The organisations: Botswana Network on Ethics, Law and HIV/AIDS (BONELA), AIDS and Rights Alliance of Southern Africa (ARASA), and, Treatment Action Campaign (TAC) each score very high on the frame classification structure outlined in Chapter 3 and are internally and externally acknowledged as rights-based. These organisations define themselves as rights-oriented, make regular reference to rights in their advocacy, articulate their struggles as grounded in rights violations and, their personnel frequently refer to themselves as human rights activists. These groups are direct in their use of the rights frame and reflect an awareness of the reasons for and results of this deliberate choice.

The organisations examined in this and the two subsequent empirical chapters are analysed systematically in order to facilitate comparison employing a structure based on the hypotheses introduced in Chapter 2 and operationalised through the method described in Chapter 3. Organisations in this chapter and the two that follow are addressed in order from most rights-oriented to least rights-oriented based on the frame classification structure. Mirroring the manner in which hypotheses were presented earlier, following a brief introduction and discussion of frame, each organisation is examined with reference to three questions. First, what are the intra-organisational factors (including personal and organisational) that influence the selection and use of the rights frame? Second, what are the factors outside of the organisation, within and outside of the country or region⁴⁵ that affect the selection and use of the frame? Third, what role

⁴⁵ For regional organisations.

do perceptions and expectations of impact have in relation to the use of rights in advocacy? Finally, following these hypothesis-led sections, two campaigns are examined in detail for each organisation to provide insight into the manner in which these various factors might interact in the process of choosing whether to employ rights in advocacy.

The rights dominant organisations examined in this chapter illustrate several important and recurrent themes. In these organisations belief in rights, particularly at the level of leadership, plays an important role in the selection of the rights frame. These groups also all began with a rights-oriented mandate and rights-oriented leadership, suggesting that such origins set organisational trajectories, and were reinforced over time. Rights oriented leaders appear to play a key role in this enterprise, creating and sustaining a rights-oriented organisational culture even in domestic settings where such discourse is uncommon. Organisational structure is important in this instance, with centralised secretariat-based structures that allow regular interaction with rights-oriented leadership appearing to be particularly important. The sole organisation of the three examined in this chapter with a decentralised membership-based structure exists in South Africa, a setting where rights is a dominant language of advocacy.

External context does appear to affect the use of rights, although its influence is not decisive. All three organisations are located in Southern Africa, and all have some degree of interaction with each other,⁴⁶ particularly at the level of leadership. The organisations in this category also have a relatively high level of international connection and, like most organisations in this sector, receive the bulk of their funding from international sources. These factors while important, do

⁴⁶ TAC played a role in ARASA's formation, BONELA has participated in training run by TAC and, BONELA is a current member of ARASA.

not appear to be key factors in the decision to use rights as a dominant frame. However, organisational niche relative to other groups in the sector does appear to be significant with two of the three groups understanding themselves as standing out from other organisations due to the rights orientation.

Finally, perceptions of impact appear critical in the decision to use rights in advocacy but in an unexpected way. Although each of these groups has a legal component, including legal clinics, and some dramatic court victories, the most important impact of rights-based advocacy was considered to be at the individual level. There is a strong association between rights-based advocacy and empowerment, and this connection is seen by many respondents as the key and distinguishing benefit of the rights frame.

4.1 The Botswana Network on Ethics, Law and HIV/AIDS (BONELA)

“As a person living with HIV you too have rights. Know your status. Know your rights.”⁴⁷

Established with a human rights mandate, BONELA is a product of a particular time in international discourse. Emerging from a UN Project Support Document in 2001 and based in Botswana’s capital city of Gaborone, BONELA has become a strong voice for rights in relation to HIV. While its origins paint a clear explanation of its initial rights orientation, its continued survival, growth and human-rights emphasis a decade later indicate other factors at play. A relative ‘voice in the wilderness,’ BONELA is understood domestically and regionally as an

⁴⁷ BONELA Radio Jingle Campaign, 2011. All primary sources are listed by organisation in the primary source list in Appendix B.

unusual Botswana⁴⁸ NGO in its focus, mission and style of advocacy. As a case BONELA illustrates support for several hypotheses. Intra-organisational factors including the initial mandate and the importance of belief, leadership and organisational structure in the development of an organisational rights culture appear particularly important. Externally, the rarity of rights-based organisations has provided BONELA with a useful organisational niche. Finally, the perceived impact of rights-based advocacy on beneficiaries has played an important role in BONELA's selection of, and fidelity to a human rights approach over time.

4.1.1 Frame

*"Our mandate is known. We do not forget why we are here. We do not forget what message we are trying to get across. So it's very important that we keep highlighting human rights as the essence of our operations"*⁴⁹

BONELA presents itself as an organisation with a primary focus on human rights, listing its mission as "to create an enabling and just environment for those infected and affected by HIV/AIDS,"⁵⁰ and to "ensur[e] that ethics, the law and human rights are made an essential part of the national response" (BONELA website – Mission, 2011). Employee impressions of BONELA's mission and purpose were congruent with this statement, with many respondents referring to integrating or mainstreaming human rights within the national HIV response, or to the tagline "making human rights a reality" for people living with or affected by the virus. (BONELA website – Vision, 2012). When discussing the primary approach that the organisation takes towards HIV, eight respondents referred to human rights, five listing human rights alone as

⁴⁸ A note on grammar with reference to Botswana: The word 'Botswana' rather than 'Botswanan' is used as an adjective. A person from Botswana is a Motswana (plural is Batswana), the language spoken is Setswana. All of these conventions are used in English as well as in Setswana.

⁴⁹ Author's interview, Employee 3, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 28 June 2010, Gaborone, Botswana.

⁵⁰ The organisation's full mission statement reads: "BONELA - the Botswana Network on Ethics, Law and HIV/AIDS - is on a mission to create an enabling and just environment for those infected and affected by HIV and AIDS. BONELA's activities are aimed at ensuring that ethics, the law and human rights are made an essential part of the national response to fighting this pandemic in Botswana, which has one of the world's highest rates of HIV prevalence. We strive to fight HIV-related stigma and discrimination and to promote respect for humanity."

the dominant approach, and three referencing it as dominant in combination with one or more other frames.⁵¹ Organisational media and documents indicated a clear human rights focus with a radio jingle campaign ending each ad with the line “as a person living with HIV you too have rights – know your status, know your rights” (BONELA n.d.), and most print materials and poster campaigns featured a rights message.⁵² An analysis of the organisation’s newsletter, *The BONELA Guardian*, shows a clear dominance of rights language, with the word rights appearing on average more than 4 times per page.⁵³ The organisation demonstrates consistency, drawing on rights language in discourse, documents, local media, and international conferences. It is also widely perceived as a rights-based organisation by other NGOs, funders, regional partners, and government.

4.1.2 Intra-Organisational Factors Affecting Frame Selection

“Obviously BONELA chose that [human rights] language because it was kind of set up like that from the start... But ... also in BONELA’s case it was very much dependent on the leadership.”⁵⁴

Formally established in 2001, BONELA was created through a Project Support Document initiative funded by the United Nations Development Program (UNDP) and the Government of Botswana. The organisation initially operated as a program of Ditshwanelo – The Botswana Centre for Human Rights (Ditshwanelo), the country’s mainstream human rights organisation, with one employee. Based in Gaborone, BONELA had more than 25 employees by 2010 and

⁵¹Two stated it was a combined human rights/public health approach, and one listed five dominant approaches (in descending order): human rights, public health, gender, equity and development. Additionally, one respondent each listed public health and legal as the organisation’s primary approach.⁵¹

⁵²A full list of all primary materials analysed and consulted for this and other cases is included in the appendix.

⁵³Newsletters from December 2003 (first issue) to Jan-March 2011 (latest issue as of April 22, 2012).

⁵⁴ Author’s interview, Christine Stegling, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 24 January 2011, Brighton, United Kingdom.

upwards of 400 members throughout Botswana.⁵⁵ BONELA has five areas of principle programming: education and training, legal assistance, a media campaign, advocacy, and research (BONELA website). Interviews were carried out with eleven employees.

BONELA's organisational history has clear linkages to human rights through its initial mandate and early association with Ditshwanelo. Influenced in part by outside forces, the group was explicitly founded to be a human rights-oriented group, and created at a time when rights discourse was in favour internationally and where funding was available to conduct work in this area. Founding Director Christine Stegling noted:

Obviously BONELA chose that [human rights] language because it was kind of set up like that from the start. There was this very strong – this is ten years [ago] 2001 was UNGASS - United Nations General Assembly Special Session on HIV/AIDS. The international policy framework started using a lot more human rights language....

But it's also in BONELA's case it was very much dependent on the leadership. I came from a human rights background. I believed in the human rights based approach. As you know, for the longest time I was the only employee of BONELA so I pushed that agenda very much.⁵⁶

Stegling's dedication to this approach, in turn resulted in the recruitment of employees with a similar orientation, and the inculcation of a human rights ethos among volunteers who sometimes, as in the case of the current director, later became employees. Over time, a human rights culture developed within the organisation with little current awareness of the

⁵⁵The group also hosts, Lesbians, Gays and Bisexuals of Botswana (LeGaBiBo), an organisation addressing the rights of sexual minorities.

⁵⁶Author's interview, Christine Stegling, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 24 January 2011, Brighton, United Kingdom.

organisation's beginnings and their impact on the organisational approach among current employees.⁵⁷

Personal commitment to human rights is a strong factor in the organisation's continued emphasis on rights. A strong personal rights affiliation is evident among BONELA respondents.⁵⁸

Passionate and effusive commentary was common.

[W]ith this respect with human rights really you can never go wrong. Human rights are the reason why we exist right? ... You have those rights, no matter how silent they are, that need to be respected. People should not trample you like a doormat. Your dignity is what will make the world. Dream.... Because dignity is human rights. It's inherent to existence as a human being. Without it imagine being treated like mud.⁵⁹

Former employees, board members and affiliates, also advocated a human rights approach and tended to have continued working in this vein,⁶⁰ indicating that the belief in this concept, whether it came before or through BONELA appeared to live beyond that connection.

When it came to explaining BONELA's human rights frame, employees were most likely to explain the organisation's approach as one of need or belief, rather than a construction relating to historical funding and discourse priorities. The theme of examining what and who is missing in existing interventions was a common thread in interviews. Not only did respondents feel that BONELA's human rights approach filled a gap left by government and non-governmental responses to the pandemic, they also frequently articulated the belief that a human rights

⁵⁷ While other respondents did not cite history or leadership as factors in BONELA's emphasis on human rights, their responses clearly reflected the existence of a strong organisational culture valuing this frame.

⁵⁸ 70% of respondents gave responses reflecting personal beliefs in human rights and who consistently referred to human rights in their interviews in ways that did not suggest strategic interests.

⁵⁹ Author's interview, Program Manager, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 28 June 2010, Gaborone, Botswana.

⁶⁰ For example a former board member is now the country representative for rights-oriented donor Forum Syd, the Founding Director now works with the HIV/AIDS Alliance, several former staff members and volunteers have gone on to work in the human rights field.

emphasis also pushed them to focus on the needs of marginalised and vulnerable groups. Five respondents specifically articulated that the use of a human rights approach is either more likely, or inherently entails looking at “different or sensitive issues”⁶¹ particularly those pertaining to vulnerable populations.

BONELA is set up to bring in a human rights response or to strengthen a government’s response to HIV through the human rights approach which mainly brings the government’s attention to populations that are marginalised because of what they are or who they are and what they do which in Botswana are mainly men who have sex with men, sexual minorities basically, you know gay, lesbian and sex workers, so that HIV interventions reach them as well.⁶²

Many respondents felt that choosing a human rights approach mandated an emphasis on groups marginalised or overlooked by other interventions. This emphasis has increased over time, with initial interventions and perceptions of the organisation’s mandate seen as targeting the broader group of people infected or affected by HIV/AIDS.

4.1.3 Extra-Organisational Factors Affecting Frame Selection

“I think BONELA found a niche”⁶³

Interplay between national and international factors has played a critical role in shaping and supporting the use of a human rights approach, providing ideas, personnel, networking opportunities and funding. While extensive international connections have been important in accessing information and funding, local context has been crucial in shaping and molding ideas to the Botswana context, a setting where BONELA has become a recognised, and to some extent

⁶¹ Author’s interview, Employee 4, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 29 June 2010, Gaborone, Botswana.

⁶² Author’s interview, Anna Mmolai-Chalmers, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 29 June 2010, Gaborone, Botswana.

⁶³ Author’s interview, Program Manager, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 28 June 2010, Gaborone, Botswana.

lone, expert on human rights and HIV/AIDS. Despite domestic isolation and fluctuations in international discourse and funding priorities over time, the organisation has remained consistent in its human rights approach.

4.1.3.1 Domestic Factors

At the domestic level, a human rights approach was viewed as distinguishing BONELA from other groups, sometimes bringing with it additional challenges. Viewed as a unique organisation within Botswana, respondents identified BONELA as filling a gap left by other government and NGO interventions.

If you look around in Botswana we are the only NGO that speaks the language of human rights in matters of HIV and AIDS. So if we were not there [there] would still remain a gap, a lacuna, in the response.⁶⁴

This impression was reflected by responses from other NGOs, donors and government who all recognised BONELA as the go-to organisation for human rights and HIV, with one respondent commenting “oh call BONELA”⁶⁵ had become the default response for assistance with any initiatives in this area. A directory of HIV/AIDS included 33 non-governmental organisations of which only one other made reference to human rights in its organisational profile (NACA 2008).

Human rights were not viewed as an approach with which to gain entrée with the Botswana government, with most BONELA employees noting that government preferred a public health approach. Roughly one-third of respondents explicitly listed government resistance when asked about disadvantages of a human rights approach. The approach was described by BONELA and

⁶⁴ Author’s interview, Uyapo Ndadi, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 27 June 2010, Gaborone, Botswana.

⁶⁵ Author’s interview, Diana Meswele, Human Rights Activist, 13 July 2010, Gaborone, Botswana.

others as being perceived as confrontational, too overt in addressing culturally sensitive issues, and associated with advocating for things that were against the law. One respondent noted:

I think people tend to think that human rights - it's a course that is for people who are anti the status quo, anti-establishment, anti-government....It seems to be advocating for human rights work or human rights respect to other people would be seen to be an adversary of the system. So I think as a result most people would rather be seen to be clean in their dealings with government ... and shy away from being seen to be combative in challenging their status quo. So I'm saying this because some organisations when you invite them to come on board and raise some of these human rights issues, they will be reluctant to do so...They wouldn't sometimes want to be seen to be at the forefront as a result of what they perceive to be being anti-establishment.⁶⁶

While some respondents noted that reference to human rights around mainstream issues such as HIV and employment was not particularly controversial, around more locally sensitive topics such as same-sex sexual activity, one activist noted that direct reference to human rights was avoided as “the moment you say that somebody's temperature goes up” and arguments were sometimes “tweaked”⁶⁷ to highlight public health in external dealings and to situate the argument within the beliefs or concerns or the target audience or decision maker.

In Botswana, consensus and consultation are highly valued and practiced, and being on good terms is considered an important factor in effective advocacy. One respondent commented on the current director, noting:

[H]e knew how to talk to the elders, okay? He knew how to persuade people. Outside of that conference room he was big friends with everybody, all these government people that you see here. But the minute that you put him inside the board room he changes and was true to himself and his constituents. He was frank and honest without offending the authorities.⁶⁸

⁶⁶ Author's interview, Uyapo Ndadi, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 27 June 2010, Gaborone, Botswana.

⁶⁷ Author's interview, Diana Meswele, Human Rights Activist, 13 July 2010, Gaborone, Botswana.

⁶⁸ Author's interview, Employee 2, National AIDS Coordinating Agency (NACA), 15 July 2010, Gaborone, Botswana.

Drawing on this cultural importance of consensus, in its use of rights BONELA has increasingly in training and internal documents made links between human rights and the concept of *botho*. This understanding was also reflected in the manner in which people spoke about human rights – as a collective, a point of commonality and of union, of human need and experience, as opposed to an individual claim against an actor. In a context where consensus and commonality are highlighted, BONELA uses rights to emphasise shared characteristics and values (ie, ‘we are all in this together’), and conciliatory techniques of dialogue are exhaustively explored as first avenues.

4.1.3.2 International Factors

While BONELA’s degree of interaction with groups outside of Botswana was cited as ranging from “not substantial” to “very often,” every respondent who noted international linkages was able to provide personal examples of interaction with groups outside of the country including attendance at conferences, correspondence and joint projects.⁶⁹

Founding Director, Christine Stegling notes that despite an international angle to the organisation’s creation, and a current high level of connection, these connections were sought out rather than given. Although BONELA’s establishment and initial funding resulted from a joint project between the government and UNDP, the organisation existed in relative isolation without substantive links to international actors including UN agencies. BONELA’s Founding Director elaborated:

⁶⁹Organisations with whom they were in touch included regional sex work organisations, the African Sex Work Movement, UN agencies, the Canadian HIV/AIDS Legal Network, individuals in the US, South Africa and Europe, the AIDS Rights Alliance of Southern Africa, the Southern Africa Treatment Access Movement (SATAMo), a “Cameroonian version of BONELA,” the AIDS Law Project (South Africa), the Treatment Action Campaign (South Africa), Gays and Lesbians of Zimbabwe, Durban Health Centre (South Africa), PRISM regional work, Men United (Suriname), AIDS Free World, Namibia Legal Aid Assistance, Southern African Litigation Centre, and the International Labour Organisation.

[R]emember, I didn't [have] those international connections ... before I started BONELA. It really was a long way in having those international connections. ...In Botswana [there was] nothing at the UN. In the end I actually called Geneva. I said, I'm sitting here in Botswana and trying to do a, b, c. ...They sent me a box...

It was a hard kind of road to get to those connections and to make those connections. Later, UNAIDS Geneva has always been very supportive of the work that I do. And some of these connections they live on until today. The Canadian AIDS Legal Network was amazingly supportive at the beginning. I used to email them relentlessly and ask them for documents. They used to email me stuff and then sometimes I wouldn't get the whole email. They would fax me single pages...

But it was a long road and a hard road. You know initially there was no – there were not many people who worked on HIV and human rights...a lot of it was really basic footwork. I remember meeting [South African Judge] Edwin Cameron in Barcelona at the [2002 World AIDS] conference. I walked up to him and I just asked him: please, please would you come to Botswana and would you help me with a workshop and he agreed.⁷⁰

Existing in relative isolation in Botswana, and with limited domestic support at the outset, the organisation researched and sought out connection with groups and individuals known to have a similar orientation for assistance with events and materials.

BONELA is now well-connected within and beyond the region. It is part of regional initiatives such as the AIDS Rights Alliance of Southern Africa (ARASA), and Pan African Treatment Access Movement (PATAM), and regularly attends international conferences including participation in every World AIDS Conference since 2002 where it has recently been actively involved in the conference's human rights stream. Despite these connections, current employees only occasionally referred to international influences playing a role in bringing in news ideas, activities or approaches and these new ideas tended to be areas of work (ie sex workers) rather

⁷⁰ Author's interview, Christine Stegling, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 24 January 2011, Brighton, United Kingdom.

than approaches.⁷¹ In addition to regional networking and participation in international events, the organisation is international from within having hosted international staff and volunteers throughout its history including 4 long term (1-2 years) volunteers.⁷² Perceptions of the influence of internationals within the organisation varied considerably, related in part to the level of personal interaction. Some felt that these individuals brought experience and skills, relating particularly to human rights, while others saw them as bringing technical skills and filling operational gaps.

4.1.3.3 Donors

BONELA receives primarily project-based funding tending to have anywhere from four to a dozen donors at any one time, each with slight, and sometimes significant, variation in its objectives.⁷³ Some of these donors have an explicit human rights focus, while others have funded BONELA under an HIV or capacity building theme.⁷⁴ BONELA found donors generally, but not universally receptive to a human-rights approach. While benefiting from current interest in funding rights-oriented projects, the organisation has retained a consistent focus over time, despite changes in the donor community.

⁷¹Some respondents noted the role of international connections in expanding and supporting work in new areas, such as sex work, and in the Prevention Initiative for Sexual Minorities where the organisation was approached by donors to expand its work on sexual minorities. Donor-initiated gatherings of funded groups in the region, or internationally, were mentioned as useful *fora* to share ideas, and to partnering with organisations in the region with specific areas of expertise.

⁷²Since very early in its history, BONELA has received international staff and volunteers, including 4 long-term (1-2 years) capacity building volunteers through World University Service of Canada, short-term interns (6 months or less) through Human Rights Internet (Canada), and volunteers through university programmes from Europe, North America and Dubai, locally-based volunteers from India and other parts of Africa.

⁷³Initially funded through the United Nations Development Program (UNDP) and the AIDS-STD Unit of the Botswana Ministry of Health, over time BONELA has tended to have a small amount of domestic funding from the Botswana National AIDS Coordinating Agency (NACA), as well as some funding from Europe (primarily Dutch and Scandinavian organisations) and North America (either American funders, and/or Canadian volunteer-sending organisations). NACA does not have an explicit human rights focus, the European donors often do, and the North American donors, with some exceptions, primarily do not. Major funders providing operation funding have included the Netherlands-based Humanist Institute for Development Cooperation (HIVOS) and, at the time of interviews, the Swedish consortium Forum Syd.

⁷⁴Other donors listed in annual reports and newsletters include: Human Rights Internet – Canada, World University Service of Canada, the Ethics Institute of South Africa, the World Health Organisations, the President's Emergency Fund for AIDS Relief, the Global Fund for HIV/AIDS, Malaria and TB, The Botswana National AIDS Coordinating Agency (NACA), Xtending Hope (Canada), the American Embassy – Botswana, The Finish Embassy – South Africa, Schorer (Netherlands), The Media Institute of Southern Africa, Center for Disease Control – Botswana – USA Partnership (BOTUSA), Ministry of Finance in collaboration with the European Union. Open Society Institute (OSI)/Open Society Institute for Southern Africa (OSISA), Netherlands Institute for Southern Africa (NIZA).

BONELA's initial funding through the PSD was tied to a human rights focus. Over the years, several funders have prioritised human rights. HIVOS, an important operational funder at several junctures, while having many funding themes and priorities, noted on their website "[t]he motivation for HIVOS support is based on the fact that BONELA's programs follow a rights-based approach in the prevention of HIV/AIDS which recognises societal vulnerability to HIV/AIDS" (HIVOS website – BONELA, 2012). Forum Syd bills itself as "Civil Society in Partnership for Excellence – Organisations Collaborating for Social Justice," and is working in Botswana with the major network organisations working in the area of HIV/AIDS,⁷⁵ of which BONELA is the only one with an explicit rights focus. While Forum Syd works in many areas, ranging from governance to poverty alleviation, and is quoted in organisational documents as primarily being oriented towards capacity building, they were widely perceived to be a human rights – oriented donor by BONELA and other sector recipients (BONELA website – Annual Report, 2007).

Reflecting on their experience at BONELA, most respondents related high donor receptivity with regards to a human rights approach, although distinctions were made between US-based and European donors. US donors, and the President's Emergency Fund for AIDS Relief (PEPFAR), in particular, was singled out by several participants as being less inclined towards a human rights approach, especially with reference to vulnerable groups such as sex workers.⁷⁶ One respondent commented that BONELA was aware of political limitations associated with

⁷⁵ In addition to BONELA, they also work with Botswana Network of People Living with HIV/AIDS (BONEPWA), Botswana Council of Non-Governmental Organisations (BOCONGO), and Botswana Network of AIDS Service Organisations (BONASO).

⁷⁶ Respondents, for example, commented on the need for caution in choosing to accept US funding, particularly in relation to sex work because of how it could limit their scope of activity.

particular donors commenting that she had been advised by a donor with whom the organisation had had a long relationship:

If you accept PEPFAR money this is what it means, this is what is happening at the U.S. at the moment [...] they have these laws about trafficking and all, so if you accept [PEPFAR money] to fund [work on] sex work know that it's going to limit you here and here. [...] So you need to be careful. Maybe it's not right for a human rights approach.⁷⁷

A significant change in the international attitude towards human rights approaches over time was noted by two respondents. One commented:

[T]here was a small dip at some point in that time, around 2004, when especially the Americans became very prominent in the policy debate. All of a sudden nobody used the language of human rights. It was all stigma and discrimination. For a few years there was this total avoidance of using human rights language, especially around the [2004] Bangkok [World AIDS] Conference...

[Now] Everybody uses human rights language. I mean no matter where. In the Ford Foundation now the whole HIV portfolio has been moved to the human rights portfolio. There is a shift. Many of the international aid agencies now require people to talk in human rights language to even access funds. It becomes a condition.⁷⁸

BONELA has clearly benefited from this shift, however, organisational documents do not reflect a tilting towards human rights in order to maximise funding. References to human rights in newsletters do not, for example, show an increase since the advent of HIVOS funding in 2004 and Forum Syd funding in 2007, both donors perceived as rights-oriented, instead indicating a slight decrease.⁷⁹ Funding trends do, however, reflect support for activities, including some direct approaches by donors, having identified BONELA's niche as being congruent with their own areas of focus. One of two respondents who noted donor initiated projects commented:

⁷⁷ Author's interview, Anna Mmolai-Chalmers, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 29 June 2010, Gaborone, Botswana.

⁷⁸ Author's interview, Christine Stegling, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 24 January 2011, Brighton, United Kingdom.

⁷⁹ In 2003, when the first newsletter was published, the word "rights" appeared 6.25 times per page, between 2003 and 2006 it appeared on average 5.352 times per page, and from 2007 to 2010 an average of 4.693 times per page.

I think we've been sort of donor-directed. Of course we are a human rights organisation and have a human rights orientation. Donors would come in and say we have funding to do 1, 2, 3, 4 and we know these are issues of interest to you. Would you like to work on it?⁸⁰

BONELA's funding landscape reflects some core donors who support, and, in some instances, explicitly request a rights-based approach. This support has enabled the organisation to continue its focus on these issues, and to weather the storms of changing discourse internationally as well as domestically. While the organisation has not chosen, and stuck to, its approach in spite of funding, neither has it shifted aimlessly in pursuit of funding over the years. With several donors withdrawing from the country in part due to Botswana relatively recent advancement to the category of 'middle income' countries, the next few years will provide a critical test of BONELA's ability to stay true to its core mandate in the face of potentially drastic changes in the funding landscape.

4.1.4 Impact

*"Knowledge of rights and entitlements it's very, very empowering"*⁸¹

While BONELA uses a human rights approach and its campaigns have had an impact within Botswana, the connection between these two factors is less than straightforward. Respondents understood rights as having an important and empowering effect on their membership and beneficiaries, but did not see rights as a mobilising tool, or make any mention of choosing this tool because of its leverage with government. While respondents espoused a consistent belief in rights language as the motivation for their areas of intervention, they at times drew on strategic non-rights language in order to further the impact of their campaigns.

⁸⁰ Author's interview, Employee 3, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 28 June 2010, Gaborone, Botswana.

⁸¹ Author's interview, Anna Mmolai-Chalmers, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 29 June 2010, Gaborone, Botswana.

4.1.4.1 Membership and Beneficiaries

Respondents made frequent mention of the impact of rights language on those involved with BONELA through training, as members, or as clients of the legal clinic. Human rights training was often linked to empowerment at the level of the individual participant. Respondents understood empowerment as an output of a human rights approach which led to an internal sense of strength, motivation and entitlement that in turn resulted in differences in behaviour, including the accessing of services, the making of demands, and health promoting behaviours such as negotiations around sex and the use of prevention methods.

To me it inculcates that [...] you are empowered to know what you are entitled to, what the other person is entitled to and in that way you are responsible for your own health and responsible for other people's health. That's the link. You claim the rights wherever you go. You go to a clinic and you are given a strop⁸² attitude you are able to act on that right. You are given the wrong medication: you are able to say okay, last time you gave me this. I hear this kind of medication can have this effect, blah, blah. Once you get the side effects you are able to inquire why you are getting the side effects like that. For me it's also being able to negotiate sex. That's empowerment along those lines. It's your right to say - sometimes it becomes as basic as saying it's your right to say no. That's the link. That's what empowerment is.⁸³

Three respondents linked a rights approach and its connection to empowerment as being connected to the success of HIV interventions. One respondent noted:

[W]e target vulnerable people therefore advantages of instilling human rights is, or maybe talking to people about human rights generally is, it will protect the target audience. It will protect so many people, even those who didn't know, even those we just trained like service providers and others will be empowered enough to own their rights, to know their rights and articulate them.⁸⁴

⁸²This is a word most commonly used in British-influenced English, thought to be derived from obstreperous, defined by Merriam-Webster as meaning touchy or belligerent. See <http://www.merriam-webster.com/dictionary/stroppy>, accessed April 23, 2012.

⁸³Author's interview, Anna Mmolai-Chalmers, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 29 June 2010, Gaborone, Botswana.

⁸⁴Author's interview, Employee 4, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 29 June 2010, Gaborone, Botswana.

Directed at individuals, rights language was used with the objective of enabling people to take ownership of their decisions in areas relating to health. BONELA respondents reflected an understanding of human rights as a process of empowerment and capacity building for the individuals with whom they work. The strength and ability to advocate on one's own behalf was seen as the natural and hoped outcome of a human rights approach.

While respondents often mentioned the positive and empowering impact of rights language on its beneficiaries, there was virtually no connection made between the use of rights language and the ability to mobilise groups of people. While membership and mobilisation have played a role, BONELA is primarily a secretariat-driven organisation with sporadic and at times incidental consultation, feedback and involvement of membership. Both the current and founding director reflected difficulties in reconciling wanting to be responsive to membership and wanting to lead in areas where their membership was not yet on board. On the one hand the process was described as: “[y]ou identify an area, an issue; and then the community buys into it; and then you do some background research; and then you develop your advocacy strategies”⁸⁵ where the organisation leads. On the other, reference was made to direct approaches by groups such as women living with HIV identifying their concerns, and to issues around prisons raised through the organisation's legal aid program. In issues of the organisation's newsletter references to membership and members were relatively rare, as were incidents of large-scale mobilisation.⁸⁶

⁸⁵ Author's interview, Christine Stegling, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 24 January 2011, Brighton, United Kingdom.

⁸⁶ From 2003 to 2010, two marches, each with over a hundred reported attendees were referenced, one with an associated petition of 10,000 signatures.

4.1.4.2 Campaigns

BONELA persists as an organisation with an explicit rights approach in its mandate and advocacy. How do these campaigns fare, and is there a connection between their impact and the use of rights language? This question will be examined with reference to two recent campaigns: 1) condoms in prisons, and, 2) an employment bill with HIV-related provisions. The first campaign is relatively contentious, while the second is a more mainstream HIV issue with widespread buy-in from other civil society groups.

4.1.4.2.1 Condoms in Prisons

Condoms are not provided in Botswana prisons due to the criminalisation of same-sex sexual activity and the view that celibacy constitutes part of the punishment of imprisonment. Nonetheless, there is evidence that sex between men takes place in prison and that HIV transmission has taken place. Because of this, BONELA has advocated for the provision of condoms in prisons as a method of intervening in the spread of the epidemic. This issue is mentioned in newsletters in 2004, 2008 and 2009, a training manual published in 2005, is featured in a poster, pamphlet and report in 2007, was the topic of a training workshop in February 2007, and is the subject of press releases issued in February 2007, March 2009 and September 2010. No other groups are known to have campaigned on this issue. An analysis of the online edition of *Mmegi*, an independent and widely read newspaper, found eight articles specifically addressing the condoms in prisons issue dating back to 2006.⁸⁷ Of these five cited BONELA (see: Moloi 2008, Mooketsi 2010, Ndadi 2010, Ngwanaamotho 2010, Segwai 2006). Of all articles making reference to the issue only one cited another NGO.

⁸⁷These are articles where this issue appeared in the headline and were the primary topic of the article.

This issue rose dramatically in profile in 2010, with increased newspaper coverage, and statements made by Former President and current chair of the National AIDS Council, Festus Mogae, and Minister of Health, Dr. Rev. John Seakgosing recommending condom distribution in prisons. After the Minister of Health's pronouncement, one newspaper noted "[t]his development comes years after BONELA has consistently asked the government to provide condoms inside prisons" (Ngwanaamotho 2010). On 3 September, BONELA's press release noted that despite these recommendations, the topic was referred to cabinet and the Vice-President chose not to review the policy. While the hoped for outcome was not achieved, the organisation does appear to be linked to the increased profile and high level support for the issue.

Human rights-based advocacy does not appear to have played a critical role in this campaign. Mentions of rights in the newsletter and training manual are in passing. The poster and pamphlet primarily feature a public health message tying the health of prisoners to the health of the population, though the poster version also contains a rights-based message.⁸⁸ In contrast, the report is clearly situated within a rights approach, with 12 pages specifically dedicated to a human rights approach (in contrast with 2 for public health) and 115 references to "rights" in contrast with 15 to "public health."⁸⁹ However, in press releases, documents which are clearly directed outside of the organisation, human rights are referenced in only one of three. In actual press coverage, BONELA is not directly quoted making rights-based references to the issue⁹⁰

⁸⁸The primary message is: "In prisons these men shouldn't be getting infected with HIV. But they are. Protecting public health includes protecting prisoners' health" with the posters also carrying the line, "When prisoners go to jail they lose their right to move freely not their right to health."

⁸⁹ The report is divided with section allocation to human rights and public health, the page count was taken from this author-imposed distinction. The word count refers to searches for the terms "rights" and "public health."

⁹⁰ BONELA Board member and lawyer Tshiamo Rantao, speaking in his capacity as a lawyer (rather than through his BONELA affiliation) is quoted as saying, "HIV/AIDS is an issue of human rights. It is not just a disease. If you deny anybody condoms, you are violating that person's right to life. The same thing applies to inmates" in Mooketsi 2010.

(see for example: Mooketsi 2010). While comments in press coverage are influenced by selections of reporters and editors, BONELA press releases do give some indication of an emphasis on the population health dynamic as opposed to a clear human rights-based argument with reference to this issue. When asked to offer an explanation for the changing profile of the condoms in prisons issue in July 2010, Former President Festus Mogae attributed to a shift away from an emphasis on human rights language.

People were saying, “they have a human right or no?” But these people, it’s a human right to be free and they deserve not to be free because they have committed offences which society punishes by imprisonment. Therefore, the deprivation they are suffering – they deserve it. That was the counter-argument against the human rights of the prisoners being violated if they are not supplied with condoms or allowed sex. The new argument says, ah! The new argument cuts both. From the human rights point of view it says yes, these people have human rights. But above all, it’s in our self-interest because these people they are married, all are married. They go to prison. They’re not going to stay there forever. Where people that go to prison HIV negative come out HIV positive and be a source of infection because they then go and infect their partners and any other person they partner with in the future when they are no longer in prison. Therefore, it makes sense that if we are looking for loopholes to plug, you are looking for new sources or sources of new infection, this is one of them. That’s why it’s being debated.⁹¹

While statements such as the above are not conclusive, it appears that a rights approach has not been instrumental or prominent in the campaign for condoms in prisons, with some indication that it may have been counter-productive. As discussed earlier, however, many respondents highlighted that a human rights approach necessitated a focus on marginalised groups, and an investigation of whose needs were not being addressed by mainstream interventions. As such, many BONELA employees saw a connection between the organisation’s human rights orientation and their uptake of the condoms in prisons issue, though not necessarily playing a key role in convincing others to take the issue on board. Respondents did indicate the strategic use of

⁹¹ Author’s interview, Festus G. Mogae, National AIDS Council, 13 July 2010, Phakalane, Botswana.

non-rights frames, particularly public health, for more contentious issues, when dealing with government.

4.1.4.2.2 HIV and Employment Law

The less contentious employment law campaign encompasses a variety of related activities calling for an employment law which specifically prohibits pre-employment HIV testing, workplace discrimination and HIV-related dismissal. BONELA began work in this area in 2002 when it began a partnership with the Botswana Federation of Trade Unions and, since then, has conducted workshops, undertaken a legal review, taken on numerous legal cases, organised a petition campaign, a march and issued press statements and publications.

Eight press releases, dating from February 2004 to 19 May 2010 were published on this topic. Of these, six had a dominant rights message, one with a mixed rights and legal angle, and one predominantly legal.⁹² HIV and employment issues featured prominently in the BONELA newsletter, dating to December 2003. The organisation created two posters addressing this issue one entitled “Right to Work,” and another titled “HIV Employment Law. Now!” which argued “[c]urrently there is no law in Botswana protecting your HIV-related rights in the workplace. Just because your health is at risk doesn’t mean your job should be.” Additionally, BONELA has created a radio jingle on this topic in which someone loses their job due to their HIV status, which concludes with the tagline “as a person living with HIV you too have rights – know your status, know your rights” (BONELA website – Radio Jingle Campaign, 2011). BONELA was involved in the formation of a coalition on this topic and gathered 13,000 signatures on a petition

⁹²The legal angle generally addressed why a law was needed over a policy – linking to enforceability.

for the law which were presented to the Home Affairs Minister in September 2007 (Keoreng, 2010). From 2006 to 2010, 14 articles appeared in *Mmegi* addressing this topic each of which mentioned BONELA, and in 7 of which BONELA appeared in the headline. A human rights approach was dominant in BONELA quotations and comments, with rights or human rights directly referred to in 9 articles, and related concepts and approaches including: discrimination, abuses, equality, stigma, indignity, prejudice, unfavourable treatment, vulnerable people and protection featuring prominently in all articles. The hoped for Employment Bill has not passed, however, there have been a several significant changes suggesting the impact of this campaign. Two editorials have come out in support of the bill, both of which make reference to BONELA (Mmegi Editor 2006; 2008). A new Public Service Act was passed in 2009, heralded by BONELA, which included the explicit prohibition of workplace discrimination based on health status (Mmegi Editor 2006; 2008). In October 2010 it was also reported that opposition MP Dumelang Saleshando intended to present a private members bill on the topic of the Employment Law. The MP noted that he had been approached by BONELA and asked to table the bill, which the organisation had also drafted (Keoreng 2010).

BONELA has been clearly linked to at least some of the landmarks reached in relation to this issue, and has primarily used a rights-based argument in relation to this campaign. Other possible arguments, such as ones based on the economic impact of excluding the very significant proportion of the workforce that is HIV positive, did not appear at all in the discourse, making it difficult to assess the comparative persuasive value of different types of argumentation. In interviews employment related issues and topics relating to discrimination based on HIV status

were listed as “very easy to use the lens of human rights” and easy to get buy in from both government and non-governmental sectors.⁹³ While condoms in prisons may have clearer links to public health, it also has far more obvious links to human rights, in that it entails the right to health and the right to life in situations where the state has a high level of control and individuals have limited autonomy. This suggests that the choice of frame was linked more significantly to the sensitivity of the issue, than to the substantive links between the topic and rights.

4.1.5 Conclusions: BONELA

BONELA has a complex relationship with human rights discourse, woven into its creation story as well as its evolution. Born of a specific mandate and nested within a human rights organisation, these initial connections proved short-lived. While they set the course for the organisation, the decision to focus on human rights was less a fork in the road and more a series of micro decisions made each day, on each project, over years. The orientation of the founding director and her influence on the development of an organisational culture provided an ongoing emphasis on human rights, and the recruitment of those who either held, or who would over time cultivate this inclination. Employees past and present demonstrated a strong commitment and belief in human rights principles, which often lived beyond their connection with the organisation.

Relatively unique within Botswana, BONELA has become known for its human rights approach and sees itself as occupying a specific niche. Initially somewhat isolated, BONELA has sought out connections with regional and international allies sharing a similar mandate and is now

⁹³Author’s interview, Uyapo Ndadi, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 27 June 2010, Gaborone, Botswana.

actively involved in a number of transnational coalitions. While at the group's outset and the present time there is a prominent favouring of rights-based approaches among donors, there has been significant fluctuation in the climate of global discourse over time and BONELA has weathered these changes, retaining a consistent core mandate and approach. The impact of human rights language was understood by respondents as primarily of a deeply personal nature, resulting in empowerment and an increased ability to claim and access services. Rights language was not seen as a mobilising strategy, nor did respondents feel that this emphasis would result in a positive outcome from government. While respondents consistently reported human rights reasons for their areas of intervention, it was not the primary message in all campaigns, with the current director noting "[s]ome arguments that do not necessarily talk human rights but the reality..."⁹⁴ were more likely to be used with more contentious topics, such as condoms in prisons.

A combination of internal organisational factors, external support over time, and a belief in the potential impact of human rights language on the organisation's beneficiaries proved critical in the organisation's continued choice of the human rights frame in its advocacy. Having established itself in a unique niche within Botswana, the organisation is now in a position where it is actively approached by donors with congruent mandates, and is recognised for its human rights expertise by various stakeholders within the country including government.

Reflecting on the hypotheses, BONELA provides support for explanations emphasising the importance of belief, leadership and organisational structure as well as organisational niche.

⁹⁴Author's interview, Uyapo Ndadi, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 27 June 2010, Gaborone, Botswana.

Individual-level impact of the frame was also viewed as critical. The group does not, however, indicate that the choice to use the rights frame emerged from a prominent local discourse, or that there were direct and consistent international or financial influences persuading the organisation to continue to choose rights as an advocacy frame over time.

4.2 AIDS and Rights Alliance for Southern Africa (ARASA)

“Our focus is entirely on promoting a human rights-based response to HIV in the region through training and capacity building and advocacy around HIV and human rights and TB now as well.”⁹⁵

Formed by human rights advocates with common concerns, ARASA was deliberately laid out with a human rights mandate. Headquartered in Windhoek, Namibia the small secretariat coordinates with its more than fifty constituent groups throughout the Southern African region. With consistent rights-oriented leadership, the group emphasises dialogue and capacity, with some seeing this as part and parcel of a human rights approach. While learning from its constituent organisations, ARASA also conducts training to increase human rights advocacy knowledge and skills in the region, in doing so serving as the bearer of rights language. In recognition of this role, at the international level the group has become a go-to organisation for groups seeking a regional voice on HIV and human rights. ARASA’s explicit rights orientation in advocacy campaigns is at times mediated by regional cultural, religious and contextual factors compelling the group to supplement or substitute a rights-based argument with regionally resonant lines of argumentation that are congruent with the rights orientation of the advocates putting them forward. ARASA illustrates support for several hypotheses, particularly

⁹⁵ Author’s interview, Michaela Clayton, AIDS and Rights Alliance for Southern Africa (ARASA), 29 July 2010, Windhoek, Namibia.

emphasising the roles of personal belief, leadership, organisational structure and niche and individual-level impact.

4.2.1 Frame

*“At the end of the day it is a human rights issue”*⁹⁶

ARASA describes itself as “a regional partnership of non-governmental organisations working together to promote a human rights-based response to HIV/AIDS and TB” (ARASA website – Who We Are, 2012). ARASA newsletters demonstrate a clear dominance of human rights with rights mentioned an average of 3 times per page.⁹⁷ All ARASA posters surveyed⁹⁸ contained a dominant rights message, as did all but one of those from other organisations displayed in the office. ARASA demonstrated consistent use of human rights language across different *fora*. The organisation conducted human rights training in the region, referred to rights in interviews, on their website, and used rights language liberally in participation in the World AIDS Conference over many years, including sitting as part of the conference’s human rights stream organising committee. The group also participated in rights-based technical and advisory groups within the UN system, and awards a rights-based award to its members.

Rights references featured prominently in descriptions of the organisation by all respondents, however, a variety of perspectives were apparent with some respondents viewing the group as employing a ‘rights based approach’ towards health or policy goals, while the founding director

⁹⁶ Author’s interview, Michaela Clayton, AIDS and Rights Alliance for Southern Africa (ARASA), 29 July 2010, Windhoek, Namibia.

⁹⁷ Due to the online, non-paginated form of newsletters in some years, 250 words was used as the per page equivalent for all ARASA newsletters and frequencies were calculated on this basis. Search terms were “rights” and “public health.” The second most referenced frame by respondents (“public health”) appeared only once every four pages.

⁹⁸ Posters observed in the Windhoek, Namibia office in August 2010.

saw the concept as the basis of the organisation and an essential outcome. With regards to the dominant frame two respondents unequivocally identified human rights as ARASA's advocacy frame. Two other respondents did not name a dominant approach when asked, instead describing the strategic selection of approaches based on which they perceived to have the greatest impact in light of a given topic or target. One respondent described "working backwards" beginning with the hoped for outcome, and assessing the choice of frame from that point.⁹⁹

4.2.2 Intra-Organisational Factors Affecting Frame Selection

*"I guess the reason we've taken that approach is that it's what I've always done."*¹⁰⁰

Internal factors were important determinants in the organisation's initial and continued use of the rights frame. At the outset rights-based groups, and individuals with a strong rights-orientation joined to form an organisation to promote and advocate within this approach in the southern African region. Over time, however, the number of partners grew substantially, and with that became a more motley crew, with a less consistent grounding in human rights, with the secretariat viewing strengthening knowledge of human rights among these groups as a critical part of its work. The group retains a strong rights orientation, seeing itself as occupying a unique niche in the region, in part due to its emphasis on rights.

4.2.2.1 Internal: Structural and Individual

Set up in 2002, initially as a project of the AIDS Law Unit at Namibia's Legal Assistance Centre, ARASA began as the coming together of five HIV and human rights-oriented groups in

⁹⁹ Author's interview, Employee 1, AIDS and Rights Alliance for Southern Africa (ARASA), 8 August 2010, Cape Town, Western Cape, South Africa.

¹⁰⁰ Author's interview, Michaela Clayton, AIDS and Rights Alliance for Southern Africa (ARASA), 29 July 2010, Windhoek, Namibia.

the region.¹⁰¹ The idea for ARASA was hatched in Geneva, where “the same suspects from Southern Africa”¹⁰² repeatedly gathered at UN meetings to discuss HIV and human rights, and sought a broader collective voice. As its name suggests, the group was formed in order to bring together groups that were working on HIV and human rights in the region. The organisation grew, and moved away from the Legal Assistance Centre in 2006. Headquartered in Windhoek, Namibia, ARASA also has offices in Cape Town and Johannesburg, South Africa. The group has eleven employees (ARASA website - About, Staff), and 51 organisational partners throughout the region. Interviews were carried out with two employees in the Windhoek Office and two employees in the Cape Town office. The group works in all member countries of the Southern African Development Community (SADC) as well as some countries in the Indian Ocean. ARASA has two primary areas of work: (1) training and capacity building and, (2) advocacy. While its focus remains on human rights and HIV, in recent years the group has added work on TB due to the high level of co-infection.

ARASA’s history is rooted in the gathering of individuals with a profound belief in and history of rights-based advocacy. Founding Director Michaela Clayton discussed how she, Edwin Cameron,¹⁰³ Zackie Achmat,¹⁰⁴ and Mark Heywood¹⁰⁵ brought together for a UNAIDS consultation on HIV and human rights in Geneva, “decided there must be other people out there doing work on HIV and human rights [in Southern Africa] and if there weren’t there should

¹⁰¹ AIDS Law Unit at the Legal Assistance Centre, Namibia, AIDS Law Project, South Africa, BONELA, SAfAIDS (Regional) and ZARAN (Zambia).

¹⁰² Author’s interview, Michaela Clayton, AIDS and Rights Alliance for Southern Africa (ARASA), 29 July 2010, Windhoek, Namibia.

¹⁰³ South African Supreme Court Justice, openly living with HIV and a known advocate in this field.

¹⁰⁴ Founder of South Africa’s Treatment Action Campaign, also openly living with HIV.

¹⁰⁵ A South African lawyer who has held leadership positions with both the Treatment Action Campaign and the AIDS Law Project.

be.”¹⁰⁶ In March 2002 a message was posted on the AFAIDS e- forum to ascertain whether civil society groups in the region would be interested in a “regional meeting on HIV/AIDS, human rights, law and policy with a view to sharing experiences and establishing a network of organisations working on these issues to facilitate ongoing sharing of experience and South-South sharing of expertise on these issues” (ARASA 2005, 1). More than two hundred responses were received from across the continent (Annual 2005, 1) and an initial meeting went ahead with 60 participants where it was “resolved to establish a regional alliance of organisations working on HIV/AIDS and Human Rights” in order to share information, act as an “alert network,” and provide training around human rights and HIV/AIDS (ARASA 2004, 2). Clearly framed from the outset as rights-based, structural features strengthened and enforced this perspective. ARASA began with 5 core organisations acting as founding trustees, four of which¹⁰⁷ have an explicit human rights approach.¹⁰⁸ Six organisations formed the initial advisory board, of which four have an articulated human rights mandate.¹⁰⁹

Individuals within the organisation also played a key role, with the director demonstrating a strong allegiance and belief in human rights. Founding and current Director Michaela Clayton came to the organisation from a legal and human rights background, and noted that human rights “always has been the approach for ARASA largely, I think, because of the fact I’ve been involved with it since the beginning. I’ve worked with HIV and human rights in Southern Africa

¹⁰⁶ Author’s interview, Michaela Clayton, AIDS and Rights Alliance for Southern Africa (ARASA), 29 July 2010, Windhoek, Namibia.

¹⁰⁷ The AIDS Law Unit at the Legal Assistance Centre in Namibia, South Africa’s AIDS Law Project, the Botswana Network on Ethics, Law and HIV/AIDS (BONELA), the Southern African AIDS Information Dissemination Service (SAfAIDS) and Zambia AIDS Law Research and Advocacy Network (ZARAN).

¹⁰⁸ SAfAIDS lists human rights as a “value” but does not list it in its mission or objective, <http://www.safaids.net/content/about-us>.

¹⁰⁹ ALP, AIDS Law Unit (Namibia), Women and Law in Southern Africa (Swaziland), SAfAIDS (Zimbabwe), ZARAN (Zambia), Lironga Eparu (Namibia – national association of people living with HIV), Programa de Direitos Humanos (Angola). Lironga Eparu – Namibia’s national association of people living with HIV/AIDS does not.

since 1988.”¹¹⁰ Tracing her own allegiance to this approach as a reaction to what she described as an initially medicalised public health approach Clayton objected strongly to a “utilitarian approach to human rights, which is human rights are good and you must protect them because it’s good for public health.”¹¹¹ She described how it is not clear some utilitarian arguments are even true but supported the human rights approach nonetheless, noting commenting:

Maybe we’re completely wrong. Maybe human rights don’t work in the context of HIV. [laughs] It’s not so much evidence-based advocacy as advocacy based on principle.¹¹²

Those who joined ARASA as it grew shared a similar commitment to human rights. Of the three employees interviewed in addition to the director, one came to the organisation from a law background, one initially from health, but having previously worked for another HIV and human rights organisation, and one from government but having worked previously for a regional HIV/AIDS non-governmental group. Most of these had previous personal experience strongly suggesting a human rights orientation: one had done a master’s in human rights, one described working in health and as a human rights activist before realising that the two pursuits shared common ground. One distanced herself from the term human rights activist, but identified herself as doing “rights-based” work.¹¹³

4.2.2.2 Partnership Dynamics

An important part of ARASA’s internal dynamics, including its choice of frame over time, involves its component parts – its fifty-one partner organisations. While a selection of these

¹¹⁰ Author’s interview, Michaela Clayton, AIDS and Rights Alliance for Southern Africa (ARASA), 29 July 2010, Windhoek, Namibia.

¹¹¹ Author’s interview, Michaela Clayton, AIDS and Rights Alliance for Southern Africa (ARASA), 29 July 2010, Windhoek, Namibia.

¹¹² Author’s interview, Michaela Clayton, AIDS and Rights Alliance for Southern Africa (ARASA), 29 July 2010, Windhoek, Namibia.

¹¹³ Author’s interview, Employee 2, ARASA, 18 August 2010, Cape Town, Western Cape, South Africa.

organisations created ARASA in the first instance and conceived of and supported its rights-based mandate, there is considerable diversity within the group – including variation in the depth of commitment, application and internalisation of human rights.

We've always been pretty open: if you subscribe to a human rights-based response to HIV, sure you can be an ARASA partner. But nobody really interrogates what that means. So when it comes to the crunch of people actually being supportive around MSM¹¹⁴ issues in Malawi, many of our organisations won't do it. They won't stand up. They often won't say why.¹¹⁵

While if someone was making public statements in direct contradiction to the ARASA's mandate the group might suggest "reconsider[ing] your partnership with ARASA" in general a dialogue approach is preferred, with one respondent stating, "where people are just reluctant because of their own prejudices I think we've agreed that the way forward is to engage rather than to sideline organisations because they don't necessarily have the same understanding of a human-rights based response."¹¹⁶

A variety of reflections were made on partnership dynamics, however, with comments ranging from "[w]e're completely led by our partners"¹¹⁷ to "we haven't had an unusual issue where the partners have almost prompted ARASA to respond."¹¹⁸ Respondents noted a variety of forms of interaction, indicating that in many cases the secretariat would lead rather than follow members on particular issues, though their approach in doing so would include a significant emphasis on dialogue and education. In many instances respondents mentioned partners in a capacity-building context, noting that part of their role was to consult and educate on matters relating to human

¹¹⁴Men who have Sex with Men

¹¹⁵Author's interview, Michaela Clayton, AIDS and Rights Alliance for Southern Africa (ARASA), 29 July 2010, Windhoek, Namibia.

¹¹⁶Author's interview, Michaela Clayton, AIDS and Rights Alliance for Southern Africa (ARASA), 29 July 2010, Windhoek, Namibia.

¹¹⁷Author's interview, Michaela Clayton, AIDS and Rights Alliance for Southern Africa (ARASA), 29 July 2010, Windhoek, Namibia.

¹¹⁸Author's interview, Employee, AIDS and Rights Alliance for Southern Africa (ARASA), 29 July 2010, Windhoek, Namibia.

rights, and to bring people together to build consensus on controversial issues. If at the outset partner organisations played a role in supporting ARASA's human rights approach, over time the ARASA secretariat appears to have been the human rights messenger, bringing the language of human rights to their membership, particularly as the number of partners have grown from groups with very similar mandates to others more loosely affiliated with the human rights approach.

Although several HIV-related regional organisations exist in Southern Africa ARASA is distinct in its mandate, primarily due to its human rights emphasis, but with respondents also noting that the group “confront[s] issues that wouldn't normally have been confronted: LGBT, sex workers, and other issues.”¹¹⁹ Two respondents contrasted the organisation's advocacy approach to that used by TAC noting that ARASA was less likely to use mass street mobilisation and often engaged more subtle tactics such as quiet diplomacy. A 2006 external evaluation of the organisation by funder the Swedish International Development Cooperation Organisation (SIDA) commented that ARASA's niche and “added value ... is unquestionable” noting that it is “the first alliance of organisations that have come together to address [a] human rights response to issues of HIV and AIDS” while commenting that “[s]till ARASA needs to clarify its identity and niche” as it grows (Chicudu and Gerntholtz 2006, 28).

¹¹⁹ Author's interview, Employee, ARASA, 29 July 2010, Windhoek, Namibia.

4.2.3 Extra-Organisational Factors affecting Frame Selection

“When you talk about health as a human right most people say of course! Everyone’s got the right to health.But when it comes to the way that policy is designed, that programs are designed, it’s a really different story.”¹²⁰

4.2.3.1 Regional Factors

Articulated strengths of the rights approach with respect to regional decision makers included the shift from an elective “policy prerogative” to “something that’s essential.”¹²¹ At the level of policy makers, human rights was viewed by several respondents as an approach that had widespread buy-in, with most parties at least rhetorically onboard, and significant backing in regional (ie SADC), continental, and international documents. One respondent commented that “[g]overnments are much more likely to listen to the arguments if you say people have human rights.”¹²² It was noted that the understanding of the implications of a human rights approach to health were not always congruent, so while a rights-supportive attitude on the part of many governments is an advantage, the disconnect between rhetoric and implementation was identified as a chief challenge.

For this reason, in part, one respondent noted that some nuancing of the approach was helpful, including piggy-backing on other issues resonating more strongly with decision-makers in order to increase the odds of uptake.

When you are talking to parliamentarians I think to be effective you have to talk to them in language that they understand. They don’t necessarily get that people have rights just because they’re people. [laughs] We could always use the combined approach that

¹²⁰ Author’s interview, Employee 1, AIDS and Rights Alliance for Southern Africa (ARASA), 8 August 2010, Cape Town, Western Cape, South Africa.

¹²¹ Author’s interview, Employee 1, AIDS and Rights Alliance for Southern Africa (ARASA), 8 August 2010, Cape Town, Western Cape, South Africa.

¹²² Author’s interview, Michaela Clayton, AIDS and Rights Alliance for Southern Africa (ARASA), 29 July 2010, Windhoek, Namibia.

everyone has human rights but in addition – and it’s really important that you do this right – in addition if you do protect rights you’re more likely to achieve public health in the context of HIV. We certainly play up or play down an element of the argument. I think there’s kind of a hazy line where you start compromising your integrity in terms of using a completely utilitarian approach to human rights; that human rights are useful as opposed to human rights are human rights because they’re human rights.¹²³

While respondents noted a high level of familiarity with at least the language of human rights amongst government representatives, this familiarity came with some preconceptions about human rights activists.

[I]f you’re going to any sort of dialogue with governments as a human rights group you’re instantly regarded in a particular kind of way. They view human rights activists as people who argue and who are just overwhelmingly critical and angry. A lot of people say to me, for a human rights activist you’re so calm! So rational! You make such good contributions! [laughter] Well, human rights activists aren’t this crazy subspecies of people.¹²⁴

A level of agitation and confrontation was associated with aspects of human rights, as noted above, with another respondent distancing herself from the term human rights activist stating “I don’t like that title.”¹²⁵

4.2.3.2 International Connections

ARASA and its human rights emphasis grew directly from international interaction, and respondents reported a high level of interaction with groups outside of the region.¹²⁶ Over time several international factors played a role in the organisation’s growth and in its human rights

¹²³ Author’s interview, Michaela Clayton, AIDS and Rights Alliance for Southern Africa (ARASA), 29 July 2010, Windhoek, Namibia.

¹²⁴ Author’s interview, Michaela Clayton, AIDS and Rights Alliance for Southern Africa (ARASA), 29 July 2010, Windhoek, Namibia.

¹²⁵ Author’s interview, Employee 2, AIDS and Rights Alliance for Southern Africa (ARASA), 18 August 2010, Cape Town, Western Cape.

¹²⁶ Respondents reported interaction with groups such as: UNAIDS, the International HIV/AIDS Alliance, and the Global Fund. Respondents made reference to collaborative projects with: Human Rights Watch, the US-based Treatment Action Group, the Open Society Institute in Southern Africa (OSISA), and a Netherlands-coordinated umbrella campaign on the Global Fund, the International Community of Women Living with HIV/AIDS, the International Gay and Lesbian Human Rights Commission, Arcus Foundation, the Centre for Reproductive Rights, the AIDS Vaccine Advocacy Coalition, the African Microbicides Working Group and the Global Campaign for Microbicides. Reference to international groups, universities, documents and agreements appeared in each annual report, with the extent of collaboration and involvement outside of the region growing over time.

emphasis, with ARASA also striving and in some cases succeeding in influencing many of the international groups it interacted with.

Some international connections had a clear internal impact, including an American activist who approached the organisation to establish a treatment literacy and advocacy program in 2006. However, the direction of flow of human rights influence more often began with ARASA and was disseminated on the international stage from there, as opposed to the reverse. The Director was part of a group that worked with UNAIDS to develop policy recommendations and was also involved over many years in the World AIDS Conference's human rights track. Tracing the integration of human rights into the World AIDS Conference, the Director, noted it began without a human rights track and eventually, in 2010 has had a human rights themed conference (Rights Here, Right Now) commenting that the impetus, "certainly was a result from pushing from a number of us working around the world on HIV and human rights to push them to take this more seriously."¹²⁷ ARASA has consistently participated in human rights related activities at World AIDS Conferences, including having a member of the secretariat speak on the 2010 Opening Plenary.

Interaction with groups outside of the region was described as "*ad hoc*"¹²⁸ and often bringing ideas that are difficult to translate into a local context.

It's actually a frustration that we deal with sometimes. People say let's have a local week of action. We're like okay, great. But to have that these are the realities that are based here: a, b, c, d, e, f, g. ... It can be difficult to get them to understand why a deal that's

¹²⁷ Author's interview, Michaela Clayton, AIDS and Rights Alliance for Southern Africa (ARASA), 29 July 2010, Windhoek, Namibia.

¹²⁸ Author's interview, Employee 1, AIDS and Rights Alliance for Southern Africa (ARASA), 8 August 2010, Cape Town, Western Cape, South Africa.

theoretically quite good may not be as good in the reality in which we work. That's I think something that we've faced often. Like with the LGBT stuff, groups wanted actions, protests. I was like actually guys, that's not really the way to go because the public opinion is not in favour of equal rights. While that doesn't mean that equal rights are not imperative there's no point in us attacking the governments if the people to whom these governments are a hell of a lot more accountable than they are to you, if those people don't appreciate it, it just fuels the idea it's western."¹²⁹

International connections within the office, in the form of previous experience, and even cultural background of staff was cited by one respondent as an advantage who noted that the organisation's take on LGBT issues might have been more conservative if they did not have staff who had spent time outside of the region.¹³⁰

4.2.3.3 Donors

ARASA respondents reflected that, in their experience, donors, many of whom had an explicit human rights emphasis, were interested in funding human rights work, however, they encountered difficulties around issues of measurement and time frames.¹³¹ One respondent noted:

Also, what a lot of donors don't understand is that it's a long-term thing. It's not going to happen overnight. It's taken twenty-five years to get to a point where human rights were central to an international AIDS conference. You know? Most funding cycles are for like three years. A year to three years; five years at the outside and they want to see results. They have to see results because they have to report to their own constituents in terms of the Swedish taxpayers or the British taxpayers.¹³²

¹²⁹ Author's interview, Employee 1, AIDS and Rights Alliance for Southern Africa (ARASA), 8 August 2010, Cape Town, Western Cape, South Africa.

¹³⁰ Author's interview, Employee, AIDS and Rights Alliance for Southern Africa (ARASA), 29 July 2010, Windhoek, Namibia. The Director was born in the UK, raised in South Africa and immigrated to Namibia in 1988.

¹³¹ According to annual reports, ARASA's funders over time have included: Irish AID, the Swedish International Development Cooperation Agency (SIDA), The John Lloyd Foundation, the Ford Foundation, the Open Society Institute for Southern Africa (OSISA), the Public Welfare Foundation, UNAIDS, the Stephen Lewis Foundation, and the Centre for the Study of AIDS at the University of Pretoria, Open Society Institute – New York, HIVOS, the Tides Foundation, and the United Kingdom's Department for International Development (DFID).

¹³² Author's interview, Michaela Clayton, AIDS and Rights Alliance for Southern Africa (ARASA), 29 July 2010, Windhoek, Namibia.

Two respondents distinguished their funders, as having a background in the issues and “who have actually come and spent a lot of time in the region and really understand the sort of work that we do and why it has an impact” referring to them as “a lot more open to accepting the vision that we have developed with partners and how this campaign should be approached.”¹³³ Several respondents noted that donors preferred visible demonstrations, stating that they “often want to fund advocacy actions but are not as enthusiastic about funding all the capacity building that goes with it” commenting that “[y]ou won’t necessarily get 200 activists marching on whatever and chaining themselves. Advocacy doesn’t always look like that”¹³⁴ and that visible actions are often the culmination of a long-term investment in community consultation and education.

4.2.4 Impact

*“the way we engage in advocacy in terms of the actions that are taken really is determined by the country in which it happens, the environment in which it happens, and being very mindful of trying obviously to do the stuff that’s most effective”*¹³⁵

The choice to use or not to use human rights language in advocacy campaigns is understood by ARASA respondents as being directly linked to, and driven by, the perception of impact. The decision of how to frame particular campaigns was influenced by the particular circumstances and sensitivities in each case, as well as the dominant arguments being put forward by decision makers, stakeholders and the public. The selection of strategies, frames and arguments for particular campaigns, in line with the above reflections, were chosen specifically for each intervention, based around government argumentation, cultural and religious sensitivities, and

¹³³ Author’s interview, Employee 1, AIDS and Rights Alliance for Southern Africa (ARASA), 8 August 2010, Cape Town, Western Cape, South Africa.

¹³⁴ Author’s interview, Michaela Clayton, AIDS and Rights Alliance for Southern Africa (ARASA), 29 July 2010, Windhoek, Namibia.

¹³⁵ Author’s interview, Michaela Clayton, AIDS and Rights Alliance for Southern Africa (ARASA), 29 July 2010, Windhoek, Namibia.

the arguments seen to be available, resonant and relevant for particular issues. Both respondents in the advocacy-oriented Cape Town office placed a strong emphasis on the importance of research and consultation in the development of advocacy strategies, with both of these, as well as capacity-building on the ground preceding mobilisation and lobbying.

Three respondents gave a detailed analysis of the steps used to determine and implement an advocacy strategy. One described it as a “top down and bottom up approach” involving mobilisation at the community level with partners around a rights-based issue, and engaging in the “policy arena” nationally, regionally and domestically “to try to make sure there are good frameworks in place that create an enabling environment.”¹³⁶ Two others elaborated on the community mobilisation side each identifying a multi-step process beginning with “understanding why people hold certain views,”¹³⁷ particularly around more sensitive issues such as sexual minorities, using this information to inform who to discuss and communicate about the issues, and then mobilising with people on the ground to understand their perspective, including identifying leaders and allies identify leaders and allies and support the community and partners in constructing a message that will resonate with target audience.¹³⁸ These respondents emphasised the importance of ownership among the community as “they’re the ones who will actually pull the advocacy together.”¹³⁹

¹³⁶ Author’s interview, Michaela Clayton, AIDS and Rights Alliance for Southern Africa (ARASA), 29 July 2010, Windhoek, Namibia.

¹³⁷ Author’s interview, Employee 1, AIDS and Rights Alliance for Southern Africa (ARASA), 8 August 2010, Cape Town, Western Cape, South Africa.

¹³⁸ Author’s interview, Employees 1 and 2, AIDS and Rights Alliance for Southern Africa (ARASA), 8 August 2010, Cape Town, Western Cape, South Africa.

¹³⁹ Author’s interview, Employee 2, AIDS and Rights Alliance for Southern Africa (ARASA), 8 August 2010, Cape Town, Western Cape, South Africa.

Like BONELA, ARASA respondents identified rights as having an important impact at the individual level. Among ARASA respondents, empowerment was not as dominant in responses as with the other two groups, but when it was mentioned, drew on similar themes as BONELA. This process was mentioned first as an internal process and viewed as being connected to building advocacy capacity, and enabling people to act on their own behalf. ARASA linked this ownership or empowerment to the ability to conduct advocacy on their own behalf, and to claim their rights rather than being passive recipients. ARASA respondents view a change in mindset as being integral to changes in policy, or the ability to claim rights.

But primarily, before anything, creating in people's minds [the idea] that they can start to challenge. If the government has crappy health services or [is] not providing health services at all, they can really take that on not for the sake of being an activist but as standing that this is something that they have to do. It's not something that they should have a choice about because ultimately this is about my life and my family's life. I have the right to demand better. I think once you create that mind shift then everything else happens. That's why a lot of our work also focuses on direct engagement with people.¹⁴⁰

Rights were viewed as making key changes in how people perceived themselves and their interaction with government. While respondents spoke of the role of rights in converting passive service recipients into active citizens, the line between active and passive violations on the part of government was also blurred. One respondent commented that a key benefit of a rights approach was “really understanding that just like you have the right to not be killed by someone in a violent action, you also have the right to not be passively killed by a government because they refuse to invest in your health.”¹⁴¹

¹⁴⁰ Author's interview, Employees 1, AIDS and Rights Alliance for Southern Africa (ARASA), 8 August 2010, Cape Town, Western Cape, South Africa.

¹⁴¹ Author's interview, Employee 1, AIDS and Rights Alliance for Southern Africa (ARASA), 8 August 2010, Cape Town, Western Cape, South Africa.

4.2.4.1 Campaigns

In line with perspectives on impact, the theme of capacity building towards mobilisation was also clear in ARASA's campaigns. In order to examine ARASA's advocacy strategies in more detail they will be analysed in reference to two recent campaigns: (1) funding for health campaign, and (2) criminalisation of HIV transmission.

4.2.4.1.1 Funding for Health

Launched in 2009, ARASA's funding for health campaign aims to increase resources for HIV/AIDS and TB from national and international sources. The campaign has addressed governments in the region, calling upon them to meet the 2001 Abuja Declaration commitment of 15% of the budget towards health, and has advocated for the replenishment of the Global Fund to Fight HIV/AIDS, tuberculosis and malaria (GFATM). Creative and multi-faceted, the campaign has included an eyeball motif on stickers and on a large inflatable balloon floated over at key events with the message "we are watching: fund the fight against HIV/AIDS and TB," as well as the "Lords of the Bling" series of youtube videos and mock US dollar bills aligning the costs spent by Mugabe, Museveni and Ghadaffi on items such as new cars or birthday parties to what the same amount could buy in terms of HIV/AIDS or TB treatment (ARASA 2009a, 2009b, 2009c, n.d.). This campaign draws primarily on numerical and epidemiological arguments to emphasise the need for a renewed commitment to HIV and TB financing, linking funding apathy to actual and projected death tolls. Using slogans such as "show me the money for health," "health is wealth," and "make it count" the group has referred to regional commitments such as the Abuja Declaration, and global commitments such as the Millenium Development Goals and the negative impact of funding decline on hoped for gains (ARASA website – Funding for Health Campaign 2011) . The group has utilised its partner organisations throughout the region

to mobilise, targeting regional and donor governments, and organising strategically around events such as the Global Fund Replenishment meetings in October 2010. The group also joined and mobilised with a continent- wide coalition of civil society groups. In 2010 the group named September 28th a global day of action for the replenishment of the global fund, with events in 10 African countries (ARASA 2010).

Of the 24 internal materials analysed, 13 made reference to rights. In most cases, rights were not the dominant theme, but were mentioned as one of several arguments. Four articles contained substantive and repeated references to rights including direct connections between funding and rights. An example of rights-oriented approach:

We believe that health is our right. We are committed to sustained, universal access to ART. We are committed to prevention and treatment for TB, malaria and other illnesses that devastate our communities. We demand that African governments and donors honour their commitments to funding for health, and close the resource gaps as needed to secure universal access to HIV and TB treatment. Through a sustained and coordinated regional campaign, we will fight for our non-negotiable right to health until it is realised (ARASA 2009d).

Rights references in documents included regional and international convention commitments, the right to health, insufficient funding and unkept promises negatively impacting on the right to health, the rights of health care workers, and general statements putting forth the need to respect human rights but not making a direct linkage to funding. The dominant argument in most documents is a health/economic argument, arguing that it is possible to meet goals such as the Millenium Development Goals, that the money is there, and that it is a crisis of priorities rather than an actual lack of funding that is the problem, particularly highlighting corruption.

In outside sources, rights references were at best occasional. This campaign was referenced three times in the South African newspaper the *Mail and Guardian* and the Lords of the Bling video featured three times on the newspaper's website. Rights were not referenced in any of the articles, nor in the text accompanying the video (Mail and Guardian website). In the five outside articles linked on the ARASA website, only one contains a reference to human rights, while in two radio interviews with ARASA staff, only one refers to rights and the reference is in relation to the organisation's mandate rather than the funding campaign itself (ARASA website).

The campaign on funding for health was described as both "simpler" than campaigns touching on cultural or religious sensitivities and "more complicated" due to its multiple targets (including public opinion, regional governments, and international donors).¹⁴² In contrast with campaigns dealing overtly with sexuality or marginalised groups or practices, funding for health is a relatively uncontroversial topic. It does not raise ire. The goal of an improved health system is not disputed. The arguments encountered are not generally that this is not a valid, relevant or culturally appropriate statement, but that there are insufficient resources, or that there is some sort of dispute over prioritisation (for example HIV prevention vs treatment, HIV vs generalised infrastructure development). In a nutshell the arguments encountered relate to ability (can we do this?) and utility (what investment will have the most significant impact?).

Correspondingly, at the policy making level respondents tended to emphasise the ability and need to make arguments couched in an economic and public health approach. Respondents

¹⁴² Author's interview, Employee 1, AIDS and Rights Alliance for Southern Africa (ARASA), 8 August 2010, Cape Town, Western Cape, South Africa.

reflected a concerted effort to understand, trace, isolate and examine the arguments made by government, noting “[y]ou can’t just be like – health is a human right, you made these commitments – keep them” and that instead, it was necessary to listen and respond to the arguments made, whittling them away until the core is revealed that, “the heart of this is really just a concern about money.”¹⁴³ ARASA countered these with arguments about priorities, and about the economic benefits over time of investing in health, but as these positive outcomes tend to fall outside of the election terms of those making the investment, it was necessarily to galvanise public opinion, who held longer time horizons and were willing to make long term health gains a political issue in the short term.

The message that ARASA targeted to the public was somewhat different, tied not to policy, but to personalising a message of health and rights. In this instance rights were raised more frequently, with one respondent highlighting the importance of a “sense of outrage.”¹⁴⁴ This was described as part of the purpose of the dollar bills campaigns, to show that healthcare “isn’t just a pipedream that we should hold hands together and sing a song” and to illustrate that “we can do it right now, but [our leaders are] not,” asking, “Doesn’t that piss you off? If it does what are you going to do about it?”¹⁴⁵ A second respondent noted the same connection between information and action, but framed it in terms of empowerment and entitlement rather than fury. She stated:

¹⁴³ Author’s interview, Employees 1, AIDS and Rights Alliance for Southern Africa (ARASA), 8 August 2010, Cape Town, Western Cape, South Africa.

¹⁴⁴ Author’s interview, Employees 1, AIDS and Rights Alliance for Southern Africa (ARASA), 8 August 2010, Cape Town, Western Cape, South Africa.

¹⁴⁵ Author’s interview, Employees 1, AIDS and Rights Alliance for Southern Africa (ARASA), 8 August 2010, Cape Town, Western Cape, South Africa.

By using the various media that we're using we know that we are penetrating people's psyches and they do understand. So that the next time they go to the clinic and they're told "oh, no, sorry we don't have this drug," they can actually ask why? It's not one of those, "oh, okay, let me just go back home. I'll come back next month. You know? They are informed."¹⁴⁶

These messages, more basic, and based on human experiences rather than policy details and financial plans were often communicated through workshops and in a capacity-building context as well as through more conventionally defined advocacy activities.

While this campaign has many dimensions, is creative in its use of varied advocacy techniques and forms of media, and has involved mobilisation on various parts of the continent, assessing its impact is not straightforward.

I mean what is the impact? We have the *Lords of the Bling* video. What is the impact of it? How do we know what does that contribute in terms of persuading African leaders that they need to actually stick to their commitments and ... to commit fifteen percent of their national budgets to health? It could have an impact. It may have an impact on civil society groups that decide well yes, this is a great thing to push for. But how you actually monitor that or evaluate that particular advocacy action as part of a much broader advocacy agenda throughout the region and how much that particular action has impacted on a final result, if there is one; it's impossible to measure. It's absolutely impossible to measure. That's a huge challenge for us.¹⁴⁷

Of the specific numerical targets articulated, 20 billion for the October 2010 replenishment of the Global Fund, and 15% of the budgets of African states dedicated to health, neither were reached. 11.7 million was put forth for the global fund replenishment and all but five countries¹⁴⁸ have failed to reach commitments made in the Abuja Declaration (Global Fund n.d.). If a basic analysis of whether and what the impact of the campaign is is complex, examining the role that

¹⁴⁶ Author's interview, Employee 2, AIDS and Rights Alliance for Southern Africa (ARASA), 8 August 2010, Cape Town, Western Cape, South Africa.

¹⁴⁷ Author's interview, Michaela Clayton, AIDS and Rights Alliance for Southern Africa (ARASA), 29 July 2010, Windhoek, Namibia.

¹⁴⁸ Including two in ARASA's region: Malawi and Lesotho.

the particular advocacy strategy may have played is significantly more difficult. Rights, however, did not play a dominant role in campaigns oriented at decision makers so, in this context, it is reasonable to conclude that rights language played a minimal role in this campaign.

4.2.4.1.2 Criminalisation of Willful Transmission

Around 2007 criminalisation of willful transmission of HIV became a significant issue in the region¹⁴⁹ with some groups, including civil society-based women's groups advocating for an HIV-specific statute. At that time a third of SADC countries had, or were introducing laws criminalising transmission of HIV (ARASA/OSISA 2007, 7). While some groups argued that prosecuting those who infect others with HIV could protect women, others, including ARASA thought that introducing such legislation would unduly target women and could result in an increase in abuse and discrimination. ARASA became concerned by this issue and, in cooperation with the Open Society Institute for Southern Africa (OSISA), hosted a regional consultative meeting "to try to get people on the same page around criminalisation"¹⁵⁰ including ARASA members and organisations who had been vocally in favour of criminalisation initiatives. The consensus reached through the consultative meeting contributed to an international consultation held in Geneva, where UNAIDS was in the process of developing policy recommendations on the subject. A global civil society coalition was also formed, which had a high profile at the 2008 World AIDS Conference in Mexico under the banner "Human Rights Now More Than Ever" which produced several documents highlighting the negative human rights impacts of criminalisation.

¹⁴⁹With several countries proposing wilful transmission statutes – Zambia, Tanzania

¹⁵⁰Author's interview, Michaela Clayton, AIDS and Rights Alliance for Southern Africa (ARASA), 29 July 2010, Windhoek, Namibia.

In organisational documents a variety of arguments were presented, including effectiveness, gender and rights. Of the six internal materials linked with the campaign on the ARASA website,¹⁵¹ five made reference to human rights. One document placed primary emphasis on gender-based arguments, and two drew on a variety of arguments but based primarily on arguments of fairness and effectiveness, three had a strong human rights emphasis. An example, of a gender and rights-based argument:

Laws that criminalise HIV exposure and transmission will further victimise and oppress women; as these laws will aggravate the risk of violence and abuse, reinforce gendered inequalities, promote fear and stigma, and ultimately increase women's risks to HIV and HIV-related rights abuses (Clayton as cited in ARASA 2009d).

A core document entitled “10 reasons to oppose criminalisation of HIV exposure or Transmission” had one explicit human rights argument, as well as 13 references to human rights throughout the text and “Human Rights and HIV/AIDS – Now More Than Ever” across the back cover (Open Society Foundation 2008). The rights-based argument (#10) was “human rights responses to HIV are most effective” arguing that [b]road criminalisation of HIV exposure and transmission threatens rights responses to HIV that empower people to avoid infection or live successfully with HIV” (Open Society Foundation 2008). This document, produced by a partnership of like-minded organisations around the world, was endorsed by 21 different groups including ARASA (Open Society Foundation 2008).

ARASA Director Michaela Clayton felt that ARASA's initiatives had been successful, in terms of building capacity at a regional level in terms of education on the topic, and enabled them to approach their own parliaments where legislation had been proposed, and feed in to international

¹⁵¹These included documents written by members of ARASA, and by the coalition of groups on this topic

policy development. She described this initiative as having “quite significantly influenced international policy on criminalisation” noting that she formed part of the group working with UNAIDS on policy recommendations in this area and that considerable attention was paid to the consensus document arising from ARASA and OSISA’s consultation, noting “[i]t was treated seriously. It wasn’t just some flakey kind of civil society definition. [laughs] It was effective on a number of levels.”¹⁵²

An analysis of the consensus document and a subsequent UNAIDS policy brief did indicate some common threads, including concerns expressed about vulnerable groups, accessibility, gender issues, stigma and the dangers of an “overly broad” application of existing statutes, as well as why it was unnecessary to create HIV-specific statutes. While it is difficult to ascertain influence, it is clear that this policy brief was done with the knowledge of the ARASA/OSISA consensus document, as it is cited in the brief. There is also clear networking, with the overlap of key personnel on various advisory boards and committees.

At the national level, Mauritius is held up as a positive example of a country that considered, and then reconsidered introducing legislation criminalising willful transmission. In June 2006 ARASA organised a workshop in Mauritius focusing on HIV/AIDS and human rights training, with some time set aside for discussion of the proposed bill. ARASA Partner organisation *Prevention Information et Lutte Contre le SIDA* (PILS) decided on the participants, “intending to use the workshop to expose some of their key constituents to information on a human rights based approach on HIV/AIDS” (Chicudu and Gerntholtz 2006, 40).

¹⁵² Author’s interview, Michaela Clayton, AIDS and Rights Alliance for Southern Africa (ARASA), 29 July 2010, Windhoek, Namibia.

The Minister of Justice was invited and asked to present on a proposed bill on HIV/AIDS which included criminalisation provisions, but chose to give a more general presentation (Chicudu and Gertholtz 2006, 40) At the time PILS did not identify itself as having a strong rights grounding, one employee interviewed by SIDA about the workshop stated:

even at PILS we didn't know much on some of the issues and [ARASA Director] Michaela was very responsive... the bill criminalised HIV transmission and Michaela did a wonderful job of locating this in a human rights and legal framework – in a very accessible and easy to understand way – she showed why criminalisation just doesn't work (Chicudu and Gertholtz 2006, 40).

By the end of the workshop, PILS had decided to make submissions to the country's Department of Justice. The group also noted the workshop had substantially changed their approach both in terms of advocacy mechanisms and content. PILS is cited as “undert[aking] a sustained campaign of advocacy on the bill and ... successful[ly] persuading the Minister of Justice to remove the provisions criminalisation HIV transmission from the bill” (Chicudu and Gertholtz 2006, 40). ARASA supported this process in several forms, with the director commenting on the draft bill, and circulating it to experts who were able to provide comments on criminalisation and harm reduction. PILS has also conducted training for members of parliament on the bill, on HIV and on human rights.

Clayton reflected on the changes, and the possible influence of her organisation. Mauritius was considering a new HIV bill in parliament which had a section on criminalisation of transmission.

It was just being in the right place at the right time. We were having a training workshop with our partners there at the time. They'd invited a lot of their partners in Mauritius. We invited the Minister of Human Rights. He was also the Attorney General at the time to do the opening address at this workshop. He did. It just so happened it was exactly at the time when they were debating this bill in parliament. We raised with him at this workshop our concerns about the various parts in the bill that were there that shouldn't be there and those that weren't there that should be there. As a result they changed the bill. Was that a direct result of our interventions at that particular workshop? Were there

other pressures being brought to bear? How much of that action actually caused that to happen? The casual link between individual advocacy actions and the end result are incredibly difficult to measure.¹⁵³

While leaping from correlation to causation is always complex, the number of direct connections discussed above, make it relatively clear that ARASA's intervention, and PILS subsequent action, had an impact on the revisions to the Mauritian bill. These interventions were also clearly articulated in a rights framework.

4.2.5 Conclusions: ARASA

ARASA's organisational history lays a clear, and obviously rights-oriented path. The group was formed by known rights-oriented HIV activists from the region, gathered for a meeting with that same emphasis, and headed by a woman with a strong rights orientation. While ARASA has grown, it still retains its original direction and is small enough that personal influences play strong role in organisational directions and recruitment. In Southern Africa ARASA is alone as a regional rights based group working on HIV. This provides a niche, but also places the organisation in a position in that is often peripheral to dominant opinion. Initially a small group of like-minded organisations, ARASA is now a partnership of 51 organisations with more diverse perspectives. At times these divergent viewpoints make it more difficult to find consensus particularly when applying a rights frame to issues that are culturally or religiously sensitive. Among its members, ARASA has come to play predominantly a capacity-building role, led by, but also leading its members, particularly where rights-education and sensitisation is concerned. With regional decision-makers, where ARASA acts directly (as opposed to through

¹⁵³ Author's interview, Michaela Clayton, AIDS and Rights Alliance for Southern Africa (ARASA), 29 July 2010, Windhoek, Namibia.

its members), ARASA also plays a rights-education role, connecting the dots between rhetoric and implementation. In many of these contexts regional forces mitigate the direct use of rights language, with ARASA seeking to respond to the dominant arguments at play among their target audience. The group receives the bulk of its funding from outside of the region, having cultivated a relationship with donors with a history in the region and an understanding of the rights approach. While connections played an important role in ARASA's formation, in later years ARASA has been the provider of human rights input and the force for emphasis in this direction as opposed to being the recipient of pressure towards rights. As a case ARASA demonstrates evidence of the impact of leadership and organisational structure on the choice to use rights, also highlighting the role of personal belief. Hypotheses emphasising the role of niche and context are also important, though the latter is a mediating factor in this instance that often downplays direct rights use.

4.3 Treatment Action Campaign (TAC)

*Campaigning for the rights of people with HIV/AIDS!*¹⁵⁴

Set up in the aftermath of apartheid, South Africa's Treatment Action Campaign (TAC) was born into a rights-aware society with constitutional reinforcements. Although TAC's ideas are clearly sourced from its domestic environment, the group was a pioneer in linking rights language to HIV and in connecting mass mobilisation, education and legal action. Recognised nationally as a strong mobilising force, the group is also acknowledged regionally and internationally, having played a key role in the formation of regional groups such as the Pan-African Treatment Access Movement (PATAM). Contextual factors have played a critical role

¹⁵⁴Treatment Action Campaign website – Banner, 2011.

in TAC's selection of advocacy strategies and the slogans and language it chooses to use, with domestic influences, both in terms of collective cultural and historical context, and the existence of legal instruments of recourse playing the most important role in the selection of the rights frame. As a case TAC demonstrates particular support for hypotheses emphasising the role of leadership, domestic advocacy and political context and expectations of individual impact.

4.3.1 Frame

“What I say is that TAC is a human rights organisation. It is the organisation that is fighting for the rights of people who are living with HIV. TAC is an organisation that needs to make sure that people’s constitutional rights are not violated.”¹⁵⁵

Rights are explicit in key organisational documents including TAC’s strategic approach, TAC’s website which is emblazoned with the banner “Campaigning for the rights of people with HIV/AIDS!” (TAC website - Banner) and the organisation’s constitution which states:

The Treatment Action Campaign supports the [South African] constitutional vision that every person is born with the inalienable rights to life, dignity, health, freedom and equality. In the context of the HIV/AIDS epidemic, the TAC aims to achieve universal access to prevention, treatment and care for all people living with HIV/AIDS and other illnesses (TAC 2008, 6).

Materials aimed at membership emphasise treatment literacy, which, while understood by respondents as a key step to rights claiming, make only occasional direct reference to rights appearing on average once every three pages in TAC’s Equal Treatment newsletter.¹⁵⁶ Posters similarly highlight treatment-literacy, with some reference to human rights such as “claim back your right to life”¹⁵⁷ or “inform yourself to stay healthy and stand up for your rights”¹⁵⁸ while a

¹⁵⁵ Author’s interview, Employee 6, Treatment Action Campaign (TAC) Ekurhuleni District Office, 25 August 2010, Ekurhuleni, Gauteng, South Africa.

¹⁵⁶ For newsletters accessed see Appendix B.

¹⁵⁷ TAC, *Know Your Medicines By Name*. Poster. Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Gauteng, South Africa, August 2010. A full list of all posters analysed is included in the South Africa source list in the Appendix B.

video of TAC's history, was peppered with activist and rights-oriented quotations such as "we don't need your permission to speak truth to power" and "now is the time to stand up for our rights" (Achmat as cited in Community Health Media Trust 2009). Where rights are referred to directly, references tended to be substantive and direct, including an editorial statement in *Equal Treatment* that "[c]entral to our campaign are the rights to life, dignity, equality and freedom of every person" (Achmat 2005, 2) and citations of constitutional provisions.

In interviews, the majority of TAC respondents refer to the group as operating primarily within a human rights framework, with one respondent noting "TAC activists are human rights activists"¹⁵⁹ and another commenting that rights are the "foundation that we're using for everything that we do."¹⁶⁰ Seven respondents made dominant or exclusive references to human rights.¹⁶¹ Comments such as "TAC it's an organisation that fights for the people living with HIV, for the rights of the people living with HIV; to have access of treatment"¹⁶² were common. Rights language was perceived as "quite consistent across audience" from the local branches to the "highest echelons" such as the World Health Organisation."¹⁶³

¹⁵⁸Poster titled "*HIV opportunistic infections can be treated!*" Poster. Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Gauteng, South Africa, August 2010.

¹⁵⁹Author's interview, Rebecca Hodes, Treatment Action Campaign (TAC) Head Office, 21 June 2011 (Telephone interview), Cape Town, Western Cape, South Africa.

¹⁶⁰Author's interview, Employee 2, Treatment Action Campaign (TAC) Head Office, 17 June 2010, Cape Town, Western Cape, South Africa.

¹⁶¹Mentioning either human rights alone or listing other factors as being components of or subservient to human rights. One respondent, when asked about frames answered "all of them" (listing religion, human rights, gender, development, law and empowerment), and one respondent saw a focus on vulnerability and vulnerable groups as being most prominent, highlighting poverty, gender and youth.

¹⁶²Author's interview, Employee 4, Treatment Action Campaign (TAC) Ekurhuleni District Office, 10 August 2010, Ekurhuleni, Gauteng, South Africa.

¹⁶³Author's interview, Rebecca Hodes, Former Employee, Treatment Action Campaign (TAC) Head Office, 21 June 2011 (Telephone interview), Cape Town, Western Cape, South Africa.

4.3.2 Intra-Organisational Factors Affecting Frame Selection

“[I]n our history in South Africa people were discriminated because of their HIV status. People were stigmatised. Still today there is discrimination.”¹⁶⁴

Founded in 1998 TAC has 72 employees, 267 branches and 16,000 members (Treatment Action Campaign 2011b) with headquarters in Cape Town and five district offices throughout the country.¹⁶⁵ TAC has received significant recognition, due in part to its successful use of the courts with regards to treatment access (see for example: Fitzpatrick and Slye 2003; Friedman and Mottiar 2004) , including a 2004 nomination for the Nobel Peace Prize (Treatment Action Campaign 2003). Heralded as, “probably the world’s most effective AIDS group” (Rosenberg 2006), the organisation lists its vision as “a unified quality health care system which provides equal access to HIV prevention and treatment services for all people” noting that “TAC will achieve this mission by ... inform[ing] and support[ing] national advocacy efforts through its branches, providing a platform for people to mobilise and organise around HIV and related health rights” (TAC website - Mission). Interviews were carried out with 6 respondents in the TAC Ekurhuleni office, and 3 head office (Cape Town) employees.¹⁶⁶

TAC’s history provides a traceable genealogy of individuals with a rights-oriented activist past. Founded on International Human Rights Day 1998,¹⁶⁷ shortly after the death of AIDS and gay rights activist Simon Nkoli, TAC grew out of a Cape Town demonstration demanding medical treatment for those living with HIV/AIDS (TAC - An Overview 2011, 2-3).¹⁶⁸ Founding leader

¹⁶⁴ Author’s interview, Employee 7, Treatment Action Campaign (TAC) Ekurhuleni District Office, 25 August 2010, Ekurhuleni, Gauteng, South Africa.

¹⁶⁵ Located in: (1) Ekurhuleni, Gauteng, (2) Gert Sibande, Mpumalanga, (3) Lusikisiki, Eastern Cape, (4) Mopani, Limpopo, and (5) uMgungundlovu, KwaZulu – Natal.

¹⁶⁶ Two current employees, one past employee.

¹⁶⁷ 10 December

¹⁶⁸ The two organisations would later diverge significantly, taking opposite stances on the government’s questioning of the effectiveness of anti-retroviral medication and advocacy of a nutrition-only approach.

Zackie Achmat, noted that he'd been "thinking about treatment for a while and asking how we could standby and do nothing while people kept dying," adding "[b]ut whoever I spoke to said it was impossible; the drugs were out of reach" (Treatment Action Campaign – An Overview 2011, 2). Nkoli's death and Achmat's own difficulties in accessing and affording treatment propelled him to action (Treatment Action Campaign - An Overview, 2011). A former anti-apartheid activist, founder of the rights oriented National Coalition for Gay and Lesbian Equality, and director of the rights-based AIDS Law Project,¹⁶⁹ Achmat was not new to rights or activism. While Achmat's own life experience played a role in the adoption of rights language, its use, in the immediate post-apartheid period was not particularly unusual.

Indeed, TAC respondents referred to the use of human rights language in a very matter of fact manner articulating rights as concrete objects reflecting reality and need rather than a choice or perspective. Responses demonstrated an inherent belief in the concept and its realisation, usually grounded in the South African Constitution and based on the country's past.

[I]n our history in South Africa people were discriminated because of their HIV status. People were stigmatised. Still today there is discrimination.... [Health] [p]rofessionals themselves will discriminate; stigmatise people who are HIV positive. They mistreat them. They treat them as if they cannot think. They treat them as lesser humans than those without, or assume to not be HIV positive. So that's how it comes. The fact that they're supposed to access treatment that is going to give them life for a long time and it's not being given at that time. It's a violation of human rights. Because of it that person does not access their treatment then, when they need it. They are supposed to go back [home]. Then their right for life has been violated. That's why I'm busy mentioning it like a human rights.¹⁷⁰

¹⁶⁹ An organisation with which TAC still actively collaborates which uses the law as a tool against discrimination and for access to care for those living with HIV/AIDS.

¹⁷⁰ Author's interview, Employee 7, Treatment Action Campaign (TAC) Ekurhuleni District Office, 25 August 2010, Ekurhuleni, Gauteng, South Africa.

At the district office respondents referred pragmatically to circumstances of discrimination as a justification for rights-based campaigning, with one person noting rights were used “because people are discriminated. That’s point number 1.”¹⁷¹ In the national office some respondents saw rights as “abstract”¹⁷² and sought to link concepts to realities on the ground in order to make them more clearly understandable, while others saw them as fundamentally accessible. Themes of accessibility, deaths, inequity, affordability and access to medications are consistently highlighted in organisational documents and discourse. Inequity on national (between rich and poor) and international levels (between countries with accessible drugs, and those without) have been key features of TAC’s advocacy throughout its history, using these comparisons, and their impacts on both lifespan and quality of life to highlight their discriminatory nature and frame them as rights violations.

4.3.3 Extra-Organisational Factors Affecting Frame Selection

“Many of us with activist backgrounds are doing old things in a new environment”¹⁷³

Domestic and international factors played an important role in the selection of advocacy strategies, with linkages to the anti-apartheid struggle and to elements of South Africa’s history and present day context playing a key role in the choice of messages and use of human rights language. While the historical explanation of rights dominance in South Africa has clear global linkages in the international response to apartheid, rights are now understood and articulated as a concept with local roots.

¹⁷¹ Author’s interview, Employee 6, Treatment Action Campaign (TAC) Ekurhuleni District Office, 25 August 2010, Ekurhuleni, Gauteng, South Africa.

¹⁷² Author’s interview, Employee 6, Treatment Action Campaign (TAC) Ekurhuleni District Office, 25 August 2010, Ekurhuleni, Gauteng, South Africa.

¹⁷³ Heywood as cited in Friedman and Mottiar 2004, 13.

Domestic factors were dominant in influencing the content and form of campaigns, which responded to local and national issues and drew on common historical experiences and contemporary realities. While TAC was unique in weaving together human rights and HIV at its outset, this new fabric was clearly created from South African materials. International connections served as useful point for information, points of comparison for global disparity-oriented mobilisation and were a source of resources.

4.3.3.1 Domestic Factors

South Africa's domestic context including its apartheid past, socio-economic disparity, AIDS denialism, and its progressive constitution have been critical and visible influences in TAC's adoption of human rights language in its advocacy campaigns. Modified apartheid-era protest songs are sung targeting pharmaceutical companies and government on HIV-related matters, or to encouraging adherence (Treatment Action Campaign 2009c). Posters compare the 2001 AIDS-related death of 12 year old Nkosi Johnson to that of 13 year old Hector Pieterse who was shot by apartheid-era police during the 1976 Soweto uprising.¹⁷⁴ TAC leaders are cited as heroes, with the names and dates of those who died commemorated in posters, referenced in songs, and recalled as reasons for TAC's ongoing campaigns.¹⁷⁵ Current battles are contextualised as the latest link in an ongoing struggle against injustice with many of the same activists using time honoured techniques on a new topic. As with earlier activism, TAC focused strongly on inequity, highlighting unequal access and distribution, naming these as

¹⁷⁴TAC, *HIV/AIDS Treatment Plan Now!* Poster. Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Gauteng, South Africa, August 2010.

¹⁷⁵For example, posters reading: "Why Civil Disobedience is Necessary: Hamba Kahle Charlene Wilson – TAC leader, sister, daughter and a comrade, Died of AIDS, 14 April 2003, aged 29, HIV/AIDS Treatment and Prevention Plan Now! Treat the People!" *Why Civil Disobedience is Necessary*. Poster. Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Gauteng, South Africa, August 2010.

discriminatory and connecting the dots between untimely death and government policy. As well as linking current to past injustices, these parallels blur the lines between active killing through violence, and passive killing through neglecting to provide care. In a TAC film for example, the Ministry of Health is referred to as having “killed” TAC members (Community Health Media Trust) due to delayed treatment roll out in line with Thabo Mbeki’s view at the time that ARVs do more harm than good. The period of AIDS denialism, under his leadership, ARV rollout and, after pharmaceutical companies offered free medication, made government ideology the obstacle to treatment. Another poster titled “stop race discrimination,” emphasised the apartheid-parallel impact of this policy, whereby those who could afford private care could access treatment, while those reliant on the public system could not.

The anti-apartheid movement involved broad-spectrum coalitions uniting diverse aspects of both society and civil society, with umbrella movements bringing together unions and other civil society groups moving towards a common cause. TAC activated some of these same connections, alliances and allegiances, launching the organisation at Cape Town’s St. George’s Cathedral, a location known for anti-apartheid protests, and drawing on familiar rhetoric to mobilise broad support from groups such including trade unions, and other NGOS working in areas including children and women’s rights (Treatment Action Campaign - An Overview, 3). These connections and allegiances were apparent at events such as the 2010 Gauteng Provincial Congress, where the Congress of South African Trade Unions (COSATU) and other organisations gave greeting, expressed support and observed proceedings.

South Africa’s post-apartheid Constitution continues to play an integral role with respondents making frequent and specific reference to the nation’s constitution. Constitutional provisions,

particularly Section 27 which provides for the right of access to health care,¹⁷⁶ were cited as almost providing an organisational mandate for the group. One respondent noted “[w]e are normally informed by the Constitution of this country, that’s our starting point” adding “[m]ost of our advocacy strategies emanated from what the Constitution says in terms of government obligations to provide services, basic services.”¹⁷⁷ Three respondents reflected the opinion that TAC’s role was intimately connected to defending, enforcing or monitoring constitutional provisions, noting “TAC is an organisation that needs to make sure that people’s Constitutional rights are not violated”¹⁷⁸ and commenting that “[i]ts job is to oversee that the government is implementing what it has promised in terms of the Constitution, Section 27.”¹⁷⁹

Constitutional references are usually grounded in rights, a terminology which has local resonance. One head office respondent noted “human rights is a very accessible discourse” elaborating that it “is part of political discourse in South Africa. It is how we understand politics at the most popular level.”¹⁸⁰ Both TAC and the South African Constitution are, in different ways offspring of the anti-apartheid struggle, with both emerging from a society attempting to define itself in opposition to a culture of state-sanctioned violations. TAC grounds itself in the Constitutional codification of these ideals, playing a role in both creating and defending these concepts through their combination of treatment literacy, citizenship education and advocacy.

¹⁷⁶Section 27 reads: “Health care, food, water and social security. 1. Everyone has the right to have access to: a. Health care services, including reproductive health care; b. Sufficient food and water; and c. Social security, including, if they are unable to support themselves and their dependants, appropriate social assistance. 2. The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights. 3. No one may be refused emergency medical treatment.”

¹⁷⁷Author’s interview, Employee 4, Treatment Action Campaign (TAC) Ekurhuleni District Office, 10 August 2010, Ekurhuleni, Gauteng, South Africa.

¹⁷⁸Author’s interview, Employee 7, Treatment Action Campaign (TAC) Ekurhuleni District Office, 25 August 2010, Ekurhuleni, Gauteng, South Africa.

¹⁷⁹Author’s interview, Employee 6, Treatment Action Campaign (TAC) Ekurhuleni District Office, 25 August 2010, Ekurhuleni, Gauteng, South Africa.

¹⁸⁰Author’s interview, Rebecca Hodes, Treatment Action Campaign (TAC) Head Office, 21 June 2011 (Telephone interview), Cape Town, Western Cape, South Africa.

TAC was recognised as holding a niche, but not one determined by the group's rights focus, which was seen as quite common in South Africa. Although it has been noted that at the time of TAC's formation "there were very few organisations with the political skill and inclination to advocate for the rights of people living with HIV," (Treatment Action Campaign 2009c, 1-2) current analysis of online directories contains at least 25 (out of 311) advocacy organisations listing HIV and human rights as their area of work.¹⁸¹ Instead respondents felt TAC distinguished itself through its treatment and rights literate membership, its ability to mobilise large numbers of people and employ the law where necessary to get results. Respondents at the national level noted that at the outset TAC had been unique, using grassroots strategies borrowed from the ANC and innovating around treatment literacy but that there have since been other groups that have developed, "essentially trying to use a similar model" and that "that might be the most important part of [TAC]'s legacy."¹⁸²

4.3.3.2 International Factors

*"TAC leadership insists that alliances need not erode its autonomy"*¹⁸³

Although domestic factors were clearly dominant and formative in TAC's creation and direction, TAC utilises a number of international connections to conduct advocacy and build international coalitions. While some information sharing occurs at these levels it does not appear to be a significant route of rights-influence on the group. Regionally, the group was integral in the

¹⁸¹ Out of a total of 311 advocacy organisations online at <http://www.prodder.org.za/> (which bills itself as "South Africa's most comprehensive directory of NGOs and development organisations"), 25 were found to be local (as opposed to regional or international) and include reference to both human rights (the terms or phrases "right to" "rights" or "human rights") and HIV/AIDS in their description of activities, objectives, areas of work, or target groups. Two groups which appeared to be for profit enterprises were excluded from the count. TAC was not included in the count as its entry contained only skeletal information including no description of activities, and containing no reference to HIV or human rights. This suggests that, if anything, the rights orientation of groups may be under-represented in this directory.

¹⁸² Author's interview, Employee 2, Treatment Action Campaign (TAC) Head Office, 17 June 2010, Cape Town, Western Cape, South Africa.

¹⁸³ Zackie Achmat s cited in: Friedman and Mottiar 2004, 24.

formation of the Pan-African Treatment Access Movement (PATAM) (Pan-African Treatment Access Movement, 2002) and is a founding member of the AIDS Rights Alliance of Southern Africa (ARASA). TAC is considered a resource and role model for other groups in the region, and is consulted and brought in to conduct training. TAC's "most strategically important allies," have been international enabling the organisation to play on corporate and government sensitivities (Friedman and Mottiar, 2004, 23). Important international civil society allies have included Medicins Sans Frontieres (MSF), Act Up, Gay Men's Health Crisis and the Treatment Action Group. TAC has successfully used international fora, such as the Durban, Barcelona and Toronto AIDS Conferences in order to put pressure on the South African government, using the international stage as a performance space of embarrassment particularly during the period of denialism TAC has managed to negotiate relatively equal relationships with international allies, avoiding subordination to western-based organisations (Friedman and Mottiar 2004, 23), understanding these linkages as reciprocal partnerships where "[t]hey are helping us a lot, as much as we are also helping them."¹⁸⁴ TAC has mobilised international support, with the formation of Friends of TAC in various parts of the world who help to raise funds, and also international mobilisations of solidarity for several global days of action which entailed letter writing and mobilisation in locations as diverse as Europe, Japan and North America (Health Gap website - Support the Treatment Action Campaign, 2003). The point of origin is one of the local experience of HIV and local connection to rights discourse, and the trajectory of influence is one that, while drawing on the international for support, solidarity and resources, remains local.

¹⁸⁴ Author's interview, Employee 6, Treatment Action Campaign (TAC) Ekurhuleni District Office, 25 August 2010, Ekurhuleni, Gauteng, South Africa.

4.3.4 Donors

TAC respondents reflected the perspective that donors were generally interested in supporting TAC's work, though several respondents noted that the funding climate had changed in recent years, citing a recession-related downturn, and a shift away from HIV funding. No respondents reported negative donor associations with human rights, nor a donor-inspired pull in this direction, and the organisation continues to work actively on HIV despite shifts in donor priorities. In both organisational documents and one interview, the importance of refusing particular funding in order to remain independent was highlighted. One respondent noted:

We do not take money from our government, of course. We are independent of them in terms of that so that we can continue to preserve our policy principle to say that we must be vocal and be able to be critical of government whenever there are shortcomings in terms of policy implementation.¹⁸⁵

The TAC website elaborates on this policy, noting that the organisation will not accept funding from the United States Agency for International Development (USAID), the South African government or pharmaceutical companies and that “[m]oney deposited in our bank account from these institutions will be returned”(Treatment Action Campaign Website - Funding and Finance, 2011).¹⁸⁶

According to annual reports, TAC funding is primarily international in origin. In the early years (2002-5) Bread for the World, Atlantic Philanthropies, Medecins Sans Frontieres, Public Welfare Foundation, AIDS Foundation South Africa, Interfund, and the South African Development Fund were dominant funders. While many of these have human rights elements in their areas of

¹⁸⁵ Author's interview, Employee 4, Treatment Action Campaign (TAC) Ekurhuleni District Office, 10 August 2010, Ekurhuleni, Gauteng, South Africa.

¹⁸⁶ Some of these explicit restrictions are likely in response to early accusations of bias, and in particular accusations by AIDS denialists that TAC was funded by the pharmaceutical companies.

work, none articulates it as a main area of focus. In 2003 HIVOS came onboard, and Open Society and the Swedish International Development Cooperation Agency became significant funders in 2004 both of whom have a more prominent human rights focus. However, most of the earlier donors continued to fund the organisation as well. A correlated shift in human rights orientation is not apparent in an analysis of TAC's work. TAC has tended to have at least a handful of donors at any one time, with much project-based funding. The 2006-7 annual report noted that 80% of funds came from 14 international donors (Treatment Action Campaign 2007).

4.3.5 Impact

TAC has seen dramatic change since its inception. Anti-retrovirals, though still not universally accessible, have been rolled out throughout the country after a lengthy and absurd battle with government and their endorsement of 'AIDS denialists' who disputed their safety and effectiveness. TAC has won several court challenges, successfully mandating the government to begin the roll-out of ARVs for the Prevention of Mother to Child Transmission in 2002. The organisation has also engaged in wide-scale treatment literacy enabling action at local as well as national levels, and the monitoring of stock-outs and inadequate treatment at health clinics. At the international level the group has advocated for generic and lower priced medication, and in cooperation with Medecins Sans Frontieres illegally imported generic medication from Thailand, and campaigned for increased funding of AIDS-related funding mechanisms such as the Global Fund for HIV/AIDS, Tuberculosis and Malaria. The role and profile that human rights discourse has played in these campaigns is varied in its form and prominence.

Similar to BONELA respondents, TAC respondents frequently linked human rights to empowerment at the individual level. Treatment literacy, in particular, was understood as the first step in claiming rights in a health care setting reflecting both a general and individual experience as many respondents began themselves as TAC members. One respondent commented as follows on the practical utility of an empowered knowledge of one's own rights and the strength to articulate them:

When you say, 'It's my constitutional right, doctor. I am not going to leave this room without having treatment,' therefore the doctor will make sure that you get the treatment ... If you freely say, 'It's my right. The *batho pele*¹⁸⁷ principle says I have the right to access services.' Patient's charter says whatever. The Constitution section [...] says this and that. With that information they make sure that you go out having found all the service that you needed. They don't make a mistake.¹⁸⁸

These demands are also backed, implicitly or explicitly, by TAC's reputation for mass action.

TAC has experienced dramatic fluctuation in its relationship with government, portrayed as an opponent or enemy of government during the denialist period and actively campaigning for the resignation of the Minister of Health, to the current situation where the Gauteng Department of Health's representative¹⁸⁹ attended the Gauteng Provincial Congress chanting "Viva TAC Viva" at the outset of her presentation, and referring to TAC as partners in the implementation and monitoring of health services. These changes, however, relate to individuals within government and their stance on HIV denialism, rather than changes in party politics or in reference to a human right approach.

¹⁸⁷ *Batho pele* is translated as 'people first' and is a government policy about improving services. A detailed description is available at: <http://www.dpsa.gov.za/batho-pele/Definition.asp> (accessed 23 May 2011).

¹⁸⁸ Author's interview, Employee 7, Treatment Action Campaign (TAC) Ekurhuleni District Office, 25 August 2010, Ekurhuleni, Gauteng, South Africa.

¹⁸⁹ Member of the Executive Council for Economic Development and Planning

Since winning an important court case, and subsequent battle for ARV roll-out the organisation has faced some challenges. Initially its mandate and objectives were very clear and easily understood, now, it is dealing with messier and more complex issues of health care infrastructure around which it can be more difficult to galvanise, communicate and monitor. Working in a context in which human rights are highlighted in the constitution, have strong political importance, and where Ministers make overt human rights references it is not surprising that TAC has relied on this strategy both for its cultural and political resonance but also for its legal support. While TAC is widely referred to from both within and without (including academic literature) as a human rights organisation, this approach does not feature prominently in every campaign. TAC's use of rights language will be examined through an analysis of two campaigns: (1) Prevention of Mother-to-Child Transmission of HIV and (2) Resources for Health. The first, arguably one of TAC's best known campaigns relied heavily on rights language, linking the words to legal recourse. The second broader and less adversarial campaign aims to support and monitor financial and human resources for health and makes limited reference to rights drawing primarily on financial and health data.

4.3.5.1 Campaigns

4.3.5.1.1 Prevention of Mother-to-Child-Transmission

TAC has been a leading player in the campaign for access to Prevention of Mother-to-Child-Transmission (PMTCT) medication and care in South Africa. Mother-to-Child or vertical transmission is a major source of new HIV infection in South Africa and prevention, while not one hundred percent effective, involves a relatively inexpensive and simple intervention, involving single dose, or short-term administration of one or a combination of anti-retrovirals before and/or immediately after birth, as well as information about breast and bottle feeding

options.¹⁹⁰ Around the turn of the century TAC lobbied very vocally for access to medication to prevent mother-to-child-transmission at a time when it was not available through the South African public health care system. When other techniques of campaigning and persuasion proved unsuccessful TAC took the Minister of Health to court in order to compel provision of the prophylactic. Despite winning a globally-reported landmark case forcing the government to begin roll-out in 2002, there have continued to be problems with access, and with providing the latest and most effective methods of prevention. As such, the organisation has had a series of interlinked campaigns on PMTCT spanning more than a decade.

TAC's argument before the Constitutional Court was one that drew precisely on Constitutional rights, basing its claim on the "Constitutional duty to take reasonable measures within available resources to achieve the progressive realisation of the right of access to health care service" (Minister of Health v Treatment Action Campaign 2002).¹⁹¹ The argument also referenced rights to basic health care for children, dignity, equality, life and "psychological integrity including the right to make decision regarding reproductive health" (Minister of Health v Treatment Action Campaign 2002). These arguments were obviously rights-based, and also the choice of this language played a critical and prominent role in their success, it provided for their justiciability.

While TAC's court challenge was explicitly grounded in constitutionally-backed rights language, its press statements have been less consistently rights-oriented. Of 18 press statements analysed on this topic five made reference to human rights with most only drawing on the term once.

¹⁹⁰Bottle feeding is generally recommended in areas with safe water with which to mix formula, otherwise exclusive breast feeding is advised.

¹⁹¹See also: "Current Developments - Preventing Mother-to-Child HIV Transmission in South Africa: Background, Strategies and Outcome of the Treatment Action Campaign Case Against the Minister of Health," Treatment Action Campaign website, <http://www.tac.org.za/Documents/MTCTCourtCase/Heywood.pdf>, accessed April 26 2012.

Reference included the right of women to choose, the right to health and the right to life. One statement read:

we have gone to courts to defend the right of women to choose and the right of children who are born to a healthy life chance. Both women with HIV/AIDS and their children have a constitutional rights to health care access.

The majority of documents focused on the numbers and details of roll-out, arguing the scientific facts of intervention. After the initial court victory, the emphasis shifted to the monitoring and advocacy of intervention and, later, as research and interventions became better studied, for the advocacy of dual over mono therapy.¹⁹² Unexpectedly, the government used the very court case that TAC had won to argue that they were restricted from only offering mono therapy because that was what was specified at the time of the court.¹⁹³

TAC's campaign on PMTCT has spanned decades and drawn on a variety of techniques, including statements from allied scientific and medical groups to support their claims, litigation, mobilisation, and domestic as well as international protest. Its successful battle against the Minister of Health was grounded clearly in rights language and this language was critical in its success as it permitted recourse through the courts. Press releases and subsequent statements, dealing with other aspects of access to PMTCT have not leaned primarily on rights discourse and have been primarily grounded in scientific and demographic data, showing evidence of effectiveness of particular drugs, and calculating both costs savings, and lives that have been or could have been saved through PMTCT interventions. After the court victory, the situation became more complex in terms of activism. In some respects direct government denial provides

¹⁹²Dual therapy is the administration of two or more drugs in conjunction instead of only one, thought to avoid problems of resistance which while not established were thought to be potential outcomes of mono therapy.

¹⁹³While the court judgment did specifically refer to mono therapy using nevirapine, it did not prohibit the use of dual therapy, or new drugs as they became available and encouraged the use of the most up to date and scientifically valid treatments.

an easy opponent for adversarial style activism, a model which also translates easily into the court system. Problems of roll-out, delays and monitoring are more difficult to address and to rectify.

4.3.5.1.2 Resources for Health

One of TAC's main current campaigns is 'Resources for Health.' Announced in June 2009, and launched through a march in July 2009, this campaign supports investment in human, infrastructure and financial resources for health and aims at achieving the South African National Strategic Plan (NSP) objectives relating to HIV and TB treatment and prevention.¹⁹⁴ The main campaign objectives are listed as: (1) "early treatment of infants, dual protocols and essential medical supplies for PMTCT," (2) providing treatment at a CD4 count¹⁹⁵ of 350 instead of 200 and eliminating waiting lists, (3) integration of HIV and TB treatment (TAC website - Resources for Health Campaign, 2009). This campaign is more holistic than past initiatives and entails actively lobbying for government, in the form of investment in the health sector. Nonetheless, TAC has employed some its classic techniques, including holding a march, pickets, and placing the theme on the back of its emblematic "HIV positive" t-shirts.

TAC's approach to this campaign makes some, but not dominant reference to rights. Documents listed on TAC's website under this campaign, are heavily NSP focused, prominently emphasising

¹⁹⁴"The NSP aims to accomplish the following goals by 2011: 1. Reach 95% of women through prevention-of-mother-to-child transmission (PMTCT) services. 2. Treat 80% of people in need of anti-retroviral therapy (ART) 3. Reduce by 50% new HIV infections." "Resources for Health Campaign", TAC, <http://www.tac.org.za/community/node/2742>, accessed April 26, 2012.

¹⁹⁵A CD4 count is a measurement of the number of CD4 cells (a type of white blood cell) in a cubic millimetre of blood. This measurement is used as an indicator of the strength of the body's immune system and, in people who are HIV positive, as a guide for when to begin taking anti-retroviral medication. In a healthy HIV negative person a typical CD4 count is between 600 and 1500. For a more detailed description see: Selina Corkery and Keith Alcorn, "CD4, viral load and other tests," NAM AIDS map, <http://www.aidsmap.com/CD4-viral-load-and-other-tests/page/1327442/>, accessed April 22, 2013.

targets with limited reference to human rights. These materials were created for TAC members to use in campaigning - thus ultimately are aimed at decision makers. The campaign-oriented banner reads "eradicate ARV waiting lists. Treat at CD4 350!" (TAC website - Resources for Health Campaign, Banner, 2009). The four page campaign pamphlet contains one section on human rights reading:

The Constitution says everyone has the right to access health care services, including reproductive health care. It also says the state must take measures, within its available resources, to achieve the progressive realisation of this right. Furthermore, the ANC has promised to prioritise health care and education (TAC, Meet the NSP Targets for HIV/TB).

The issue is framed in this document in the context of a dramatic drop in life expectancy related to HIV and TB and the dramatic impact of this on the health care system (TAC, Meet the NSP Targets for HIV/TB, 2). TAC's memorandum relating to this campaign contains one rights-oriented section out of ten pages. This section titled "Health Rights, Human Rights, HAART¹⁹⁶ rights" which contains a single paragraph which is explicit in its rights framing. It reads:

This is both a moral outrage and a waste of precious health resources. The Constitution guarantees the progressive realisation of access to comprehensive health care. Long ART waiting lists and stock-outs of ARVs and other essential medicines violate this right and sacrifice the lives and well-being of HIV positive South Africans (TAC, Fund the Fight Against HIV and TB, 2009).

Campaign documents include 17 suggested slogans. While all activist and mostly adorned with exclamation marks, only one uses the word rights.¹⁹⁷ Of the 45 press releases and statements

¹⁹⁶Highly Active Anti-Retroviral Therapy. "Fund the Fight Against HIV and TB:TAC's Resource or Health Memorandum," TAC, 7 June 2009, http://www.tac.org.za/community/files/RFHMemo_2.pdf, accessed April 26, 2012.

¹⁹⁷Slogans: Needs based Budgeting = Lives saved!, Universal Access to Treatment NOW!, Treatment is Prevention!, Meet the NSP targets for treatment and prevention!, Our struggle continues: human resources for health!, Waiting list = death row, HIV/TB is not in recession!, Economic recovery must include health recovery, Knock-out the stock-out!, If targets are missed - we die!, Decent work for community healthcare workers., President Zuma/Minister Motsoaledi - save our lives!, Fund the fight against HIV/TB., Government - protect our lives! increase public health spending, The nation is watching - Deliver on promises for child and maternal health now!, We still have rights in a recession!, No more BROKEN promises, no more BROKEN lives, FIX our healthcare system, Public health is a global public good (Treatment Action Campaign website - Resources for Health Campaign 2009, 9).

issued only 11 make any reference to rights.¹⁹⁸ Of these the vast majority made one or two references¹⁹⁹ with rights not being the primary orientation of any one document. Where rights are referenced it tended to be the right to health and the state's constitutional obligation to provide it with comments such as "[t]he right to healthcare depends on properly paid health care workers" (TAC and Section 27 Statement, 2010). The right to life was also noted: "[t]he availability of resources for HIV/TB is the key determinant of whether or not the right to life for millions of Africans will be realised"(TAC website - Resources for Health Campaign 2009). The dominant focus in each of these documents tended to be details of ARV roll-out, impacts on health, government and international responsibility, and the link between funding and life, or lack of funding and death.

External press coverage illustrates an even firmer focus on numbers, logistics and outcomes. Eleven articles in the weekly *Mail and Guardian* newspaper mentioned TAC on topics connected to the resources for health campaign in 2009-2010. In the majority of these TAC was cited as a source of what the reality on the ground was in specific areas, or calling for increased funding, or questioning the availability of resources. In none of these articles was TAC, or the resources for health campaign the primary focus, nor was there any reference to human rights in quotations or descriptions attributed to TAC.

It is difficult to assess the impact of TAC's campaign, given that it is premised primarily on stated government objectives and, as such, there is presumably an internal push to meet these

¹⁹⁸Listing of organisations having rights in the name were not included.

¹⁹⁹The highest frequency was a document with 17 references. Note: statements posted in the press releases section are varied in form, content and origin, they are sometimes attributed, sometimes from TAC in cooperation with another organisations, and sometimes re-posted items from linked organisations, and occasionally people posting in their personal capacity.

targets. It is also a complex and, while it contains targets, a broader and more general campaign with wider-ranging objectives involving domestic and international investment in the healthcare system.

Accounts of projected and actual stock-outs (particularly in the Free State) were reported in 2009, with press reporting “little progress on appointing additional nurses and doctors” (Mail and Guardian 2009). Some progress has been made towards these objectives, however, with the Minister of Health announcing in December 2009 that government policy would change in April 1 2010 to put pregnant women and those infected with both HIV and TB on ARVs at a CD4 count of 350 (as opposed to the previous 200). TAC was frequently cited in media reports to provide an independent assessment of the achievement of these and other claims of implementation. In February 2010 TAC announced that it was “pleased with the additional funds that will be made available for HIV programmes and that the government is projecting to meet the target of the HIV/AIDS and STI Strategic Plan” but continued to express concerns about funding for tuberculosis and about whether money was being used as effectively as possible (TAC website - 2010 Budget Review, 2010).

Analysis of this case presents a series of facts and variables: that the government set objectives, that TAC set a campaign to reach these objectives, and that some success has been attained, that in outward-oriented statements (ie not directed at membership) rights discourse was used relatively infrequently, and that TAC was frequently cited by the press in its capacity as an expert or in its on-the-ground monitoring capacity. TAC engaged in dialogue on the topic, held several well-attended events, communicated with government, and was recognised as being a source of expertise and a way of verifying the implementation of government claims. This can be considered a partial success in a mammoth campaign, though given the limited profile given to

human rights it is unlikely that this played a significant role. TAC's influence hinged most on its known expertise, and recognised ability to monitor and mobilise in this area, as well as an acknowledgement by the Department of Health of the group's utility as a critical, but important partner.

4.3.6 Conclusions: TAC

While many factors have played a role in TAC's adoption and continued use of human rights language in advocacy, domestic influences have been the most prominent. Internally, the group traces its rights orientation through its people, with its founder a former anti-apartheid activist with a clear rooting in human rights discourse. Respondents reflect a matter of fact understanding of rights, stating the existence of inequality itself as the explanation for the rights frame. In post-apartheid South Africa rights form an integral fibre of the collective fabric of the nation. Rights is a common language in South Africa, one that is understood, and resonates and translates easily between issues. It is a language with which the governing African National Congress (ANC) is familiar and has used, advocated and promoted.

The perceived impact of rights language featured prominently in respondents' comments about this choice of advocacy strategy. TAC employees felt that rights language, in combination with treatment literacy, brought strength to the individual enabling them to claim appropriate health care, and to wield the possible consequences of an informed, organised and activist group if their needs were not met. TAC's power to mobilise large groups of people is well recognised, and the group understands itself as a movement. If at an individual level knowledge and use of rights terminology empowered people living with HIV to access health care at their local clinics, at a national level TAC relied on the same language in order to compel the broader provision of

health care services nationally. TAC, however, has drawn on this language with varying depth and frequency as the issues have changed. The move from an oppositional government supporting denialist approaches, to one supporting conventional medical approaches has paved the way for a shift from a very adversarial relationship to one referred to in the language of partnership. Along with the change in environment, there has been a shift in advocacy campaigns, with a current emphasis on resources for health, a campaign in which rights language has been less prominent. It could be that rights language is better suited to more adversarial campaigns. TAC is now faced with the challenge of monitoring government, working to support them, but also remaining critical. On the ground, the group faces challenges with a more nuanced campaign, and a lack of understanding of their continued campaigns given the change in circumstances and roll-out of ARVs.

As a case TAC demonstrates support for hypotheses which emphasise the role of leadership and the importance of domestic context. In this case the local grounding of rights played a very important role in their initial and ongoing adoption as an advocacy frame. In TAC's case, hypotheses about the individual-level impact of rights-based advocacy are also supported, with an additional understood link to mobilisation and possible legal action if such individual-level rights claims are not satisfied. TAC does not illustrate support for hypotheses which highlight international factors as critical in the adoption of the rights frame, and the organisation has vocally rejected claims of financial interference as well as sources of funding that they believe would compromise their independence or integrity.

4.4 Rights as a Dominant Frame: Comparison and Conclusions

These three cases illuminate some important recurrent themes revealing the potential explanatory power of some hypotheses while suggesting that others hold less leverage. These three cases highlight the importance of belief, leadership, organisational structure and context in the decision to choose rights. In each organisation there is demonstrated belief in the rights frame, with responses from employees that suggest a personal commitment to rights, in some cases divorced from outcome. Organisational history and leadership also play a significant role, shaping the organisation's set up and subsequent hirings. In two of three cases (BONELA and TAC) there has been a change in leadership but the rights emphasis has remained, while ARASA still has its founding director. The organisational structure in two of three groups (BONELA and ARASA), also appeared to facilitate the ability of leaders with a strong rights orientation to have a strong impact on organisational culture, in that they began as quite small secretariat-based groups where all employees had regular interaction with leadership. The remaining organisation TAC, has a decentralised structure, but also exists in an environment where rights are a common discourse of advocacy and thus is less likely to rely on the incubating effect of a small centralised office with a rights-oriented leader.

External factors have also been important demonstrating the impact of influences from within and outside of the region, and funding. These three cases illustrate an interesting interplay between local, regional and international factors in rights discourse, each with differing origins of their rights frame. In each case national or regional perspectives on rights shaped the manner in which this language was used and understood. Local factors play a dominant and important role in the manner in which rights are used in advocacy, although these influences do not pull

uniformly or even in the same direction. In BONELA's case, the impetus for rights came in part from international sources (UNDP) but was localised over time calling to norms of consensus and consultation, while in TAC's case, the language of rights is very much local and calls to more adversarial traditions emerging from the anti-apartheid struggle. ARASA, as a regional organisation, emerged from existing regional rights activists and now serves primarily as the regional bearer of rights through training and capacity building. While all groups were successful in continuing to source funding, predominantly from outside of the region, this appears to be a supportive factor rather than a directing factor with respect to the rights frame. Also, as project-based funding became more common the groups targeted their funding proposals according to donor preferences, and, as the groups became better known, they also starting being approached by donors who appreciated their approach.

The connection to impact was not always direct. TAC and ARASA saw rights as being a language governments responded to, though ARASA respondents expressed frustration with the sometimes dramatically different understandings in what rights mean in practice. BONELA, on the other hand, found rights were often a barrier in communicating effectively with government. The most important contribution of a rights based approach was understood as the effect that the frame had on individuals. All three groups saw rights as having an important empowering impact. Rights were viewed as distinctive from other approaches in holding the power to change the way in which individuals understand the relationship between themselves, others and the state. This transformation in perspective was seen as a necessary and critical precursor to a shift in behaviour, prompting more active, assertive and rights-claiming behaviour, particularly in the health care setting.

Chapter 5: Rights Mixed: Organisations that Use Rights Amid Other Advocacy Frames

Some organisations, as examined in the previous chapter, make a strong and deliberate choice to emphasise rights in advocacy. Others, as the subsequent chapter will explore, make limited or no use of rights. Caught between these two poles are groups who employ rights but who do not use them as a primary advocacy frame. This chapter analyses three organisations that use rights in advocacy on some topics, in some settings, or who do so in combination with other frames that are given equal or greater emphasis. The organisations: National Community of Women Living with HIV/AIDS (NACWOLA), Southern African HIV and AIDS Dissemination Service (SAfAIDS), and The AIDS Support Organisation (TASO), each score in the mid-range of the frame classification structure. They are categorised as ‘rights mixed’ due to their use of rights alongside other advocacy frames.

These three organisations illustrate several key trends distinguishing them from the rights dominant groups discussed in the previous chapter, with notable differences relating to intra-organisational factors, extra-organisational factors and perceptions of impact. First, at the intra-organisational level, personnel articulate a more limited scope of rights, often speaking of rights as a specific topic applying to some issues and not others. Consequently, the frame is used more sparingly by these organisations than by rights dominant groups who understand rights as an over-arching frame holding near universal application. Groups in the rights mixed category are also more likely to have decentralised membership-based structures, to draw personnel from their target constituency, and to list personal experience as influential on frame choice. Second, extra-organisational influences on frame were more frequently cited by respondents in rights mixed organisations than in those using rights as a dominant frame. Domestic coalitions, local

norms and international conferences, linkages and volunteers were listed as factors that had an impact on frame selection and use. Groups would, for example, adopt a frame introduced by a domestic coalition or international volunteer but tended to do so only with respect to the particular campaign or topic being addressed by that actor. The groups in this category are also situated in less rights-oriented environments, with two of the three groups in Uganda, further from the influence of rights-oriented South Africa. Using multiple frames, groups in this category hold organisational identities and niches based on target constituency (the ‘who’ of advocacy) or method of advocacy (the ‘how’) rather than frame (the ‘what’). Third, rights mixed organisations are far more likely to associate impact with the needs of the constituency being represented, or the appropriateness of the process of advocacy than with the frame used.

Grouped only by a partial commonality (some use of rights), organisations in the mixed rights category differ significantly among themselves with notable variation in when, how and why they use rights as well with respect to what they use alongside or instead of rights. These groups do not display the common factors shared by the organisations in Chapter 4 which result in adoption of rights as dominant frame. Organisations in this category illustrate frames which are split across a number of possible divides. Within some groups there is a hierarchical or geographic division in perceived organisational frame, with, for example, those at regional offices, or lower levels less likely to rely on human rights language, than those in national offices and leadership positions. In others, the division is less systematic and varies by campaign. This variation can be linked to partner organisations, the campaign theme and its perceived resonance with rights or the extent to which the person organising the campaign holds a rights orientation. Rights orientation can also vary over time and, as such, be correlated to the length of time particular individuals have spent with the organisation, or to particular time periods in the

organisation's history. For example, a group that started out with a rights emphasis, may have rights-oriented founding members, but a less clear, different, or more diverse advocacy frame among those who are more recent employees.

Among the three cases examined here rights appear as one of several approaches, sometimes on equal footing with other frames such as development or gender and in other cases subordinate to a dominant organisational process (such as dialogue) or identity (such as a group of women living with HIV/AIDS). Because mixed or selective use of rights can manifest in several different configurations as discussed above, there is considerable variation between the groups analysed in this chapter. In comparison with the rights dominant organisations there is also significant variation within this group with regards to the level of documentation available. As such, this is a more heterogeneous group than that examined in the previous chapter. This chapter also marks the beginning of a shift, becoming even more pronounced in the following chapter, from predominantly examining evidence explaining the occurrence of a phenomenon (the use of rights) to analysing evidence of the partial or complete absence of that same phenomenon. This is a more complex task, often involving more indirect sources of information, as respondents are usually less likely to document, remember and reflect on, the road that was either "not taken" (Frost 1920) or, in the case of this chapter, not travelled to its final destination.²⁰⁰ Consequently, although this chapter tackles the same research question as Chapter 4 (why do groups choose rights?), when examining mixed or negative cases two additional

²⁰⁰Conversely, Frost's pronouncement that "I took the road less travelled by and that has made all the difference" (Frost 1920) is more likely, as discussed in the previous chapter, with particular reference to BONELA, to be used as an explanatory creation story.

questions are implied: 1) why do groups not choose rights? and 2) why do groups choose the frames they do?

This chapter examines three organisations who utilise rights amid other approaches in their advocacy. The groups are addressed in descending order of rights emphasis: (1) the National Community of Women Living with HIV/AIDS (NACWOLA), Uganda, (2), the regional Southern African HIV and AIDS Dissemination Service (SAfAIDS), and, (3) The AIDS Support Organisation (TASO), Uganda. As in Chapter 4, these groups are systematically examined and compared with reference to frame classification, intra-organisational factors, extra-organisational factors and perceptions of impact. Process tracing of campaigns is then undertaken to analyse how these factors converge in practice.

5.1 National Community of Women Living with HIV/AIDS (NACWOLA)

“We are not the Problem, but Part of the Solution”²⁰¹

NACWOLA’s identity is firmly and explicitly linked to the group’s status as an organisation of and for women living with HIV. The national organisation has members and branches throughout Uganda and conducts advocacy, provides support and invests in capacity building for women and their children. Within this gender-based identity, however, the group draws on a variety of advocacy frames and strategies with rights readily, frequently and substantively referenced, along with development, public health, equity, gender and other frames. These frames are considered to hold roughly equal weight, with rights seen as neither peripheral nor overarching. The group has changed over time shifting increasing emphasis to advocacy and

²⁰¹NACWOLA 2008, 1.

rights in the past five to six years while maintaining a strong element of support for its members and their families. In some ways this group has features suggesting the transition to a rights-based advocacy group from a more support-based membership organisation indicating some of the intermediary steps that may occur when and if groups morph in this direction over time.

As a case NACWOLA suggests support for some of the hypotheses posited in Chapter 2. Intra-organisational factors such as the previous work and personal experience of personnel and leadership play an important role in influencing the group's advocacy frame, and in shifting the organisation's approach towards rights. Extra-organisational factors such as domestic coalitions and international connections which introduce the group to the rights frame in relation to particular campaign topics influence the manner in which advocacy is framed on these topics. Perceptions of organisational identity, niche and impact, however, are tightly linked to the organisation's key constituency of HIV positive women and their children. This identity is reinforced and grounded in the group's membership-oriented decentralised structure. NACWOLA employs rights as a useful tool, but as one tool among others with which to advocate for HIV positive women and their families in Uganda.

5.1.1 Frame

*"we look at HIV as a cross-cutting issue, there is no specific thing where you say – 'oh it is only a development issue,' or 'oh it's only health,' but for us, of course, as people infected with HIV we look at it as a cross-cutting issue from health, to poverty, to human rights."*²⁰²

Rights were referenced with relative frequency in NACWOLA interviews and documents, but were consistently listed as one dimension of the organisation's work and focus rather than a

²⁰² Author's interview, Employee, National Community of Women Living with HIV/AIDS (NACWOLA), 29 March 2010, Kampala, Uganda.

dominant theme. In interviews most respondents described NACWOLA's frame as multifaceted, with at least two but often as many as five or six different points of orientation, usually including rights as one of these. Other key frames that were frequently referenced include: gender, development, health, poverty, equity and support. Of these gender and rights were most prominent, followed by development and poverty alleviation.

Materials displayed in the national office also evidenced some, but not dominant, rights emphasis. Of the materials observed²⁰³ three were externally produced and did not mention rights. The single NACWOLA-produced material, a framed poster titled "NACWOLA's philosophy," listed the vision, values, goal and main objectives of the organisation (NACWOLA n.d.). Among these various organisational statements a gender focus was the most prominent, although rights did also feature in several locations. NACWOLA's stated vision is "a society of women living with HIV/AIDS who are healthy, happy and productive with their rights and responsibilities upheld in order to live a meaningful life," for example, and the group's "overall goal," is listed as "to reach out to an increasing number of women living with HIV and their families to benefit from effective programme interventions that fulfill their rights and aspirations" (NACWOLA n.d.). Organisational values do not mention rights, but include qualities such as social justice, love, support, honesty, empathy and sharing. Of the organisation's more specific four main objectives, one references rights, stating the group exists to "advocate for the rights of women living with HIV" while other objectives highlight unity, fighting stigma, and support (NACWOLA n.d.).

²⁰³ All posters observed in the National Office in March 2010.

Organisational documents contain some, but not dominant reference to rights. Rights appear roughly once every one and a half pages with slightly more references occurring in the more recent of the two documents analysed. The earlier document, *The Transformation of NACWOLA 2004-2007*, dedicates the most space to support and livelihood initiatives, with rights primarily referenced as “rights-based approaches” often with limited substantive elaboration. In the more recent document, *National Community of Women Living with HIV/AIDS in Uganda*, rights receive significant mention, with a dedicated two page section. Human rights are referenced in the following manner:

NACWOLA brings together women and girls living with HIV/AIDS who have identified key actions to improve their situations, including demanding recognition of their fundamental human rights; calling for meaningful involvement at all stages of the decision and policy-making process, advocating for their sexual and reproductive rights, including the right to decide whether or not to have children; and urging governments to provide accessible, affordable and equitable healthcare (NACWOLA 2010: 14).

It is clear here that rights and gender are understood as intertwined approaches. While human rights are “included” as an important area of work, they are one key area of focus rather than an all-encompassing theme. In this document, for example, rights receive no mention in the executive summary, a place where one would expect to see evidence of the dominant organisational perspective. In contrast, the summary contains fifteen references to gender (women, girls, gender, mothers) highlighting the importance of the group’s constituency-based identity. In this publication the phrase “we are not the problem, but part of the solution” graces the top of each page, and the back cover holds the quotation:

NACWOLA is the only organisation in Uganda run by HIV+ women for HIV+ women. That makes us unique and enables us to design our programmes according to the women’s actual needs (NACWOLA 2010).

This is the key niche of NACWOLA, and from which the organisation derives its strength, relevance and identity. Within this fold, rights have become more prominent over time, but continue to exist amid other important approaches, rather than overtop of them.

5.1.2 Intra-Organisational Factors Affecting Frame Selection

“human rights is a new thing”²⁰⁴

The National Community of Women Living with HIV/AIDS (NACWOLA) was established in 1992 by three women living with HIV and informed by their personal experience of living with the virus. The organisation was founded immediately after the three returned from the 8th International Conference of the International Community of Women Living with HIV/AIDS (ICW) in Amsterdam. Headquartered in Kampala, the group has grown to a national network with a national membership of more than 600,000, and a presence in 30 districts, including offices in sixteen districts and branches of members in the remaining fourteen. NACWOLA has fifteen staff in its Kampala headquarters, where interviews were carried out with six employees. Organisational documents list four core program areas: (1) advocacy and networking, (2) positive prevention, (3) peer psychosocial support, (4) human rights and HIV/AIDS. Additionally the group is involved in livelihood support, memory books, policy advocacy, stigma and discrimination and has a significant focus on children. Advocacy and human rights are both issues which have risen in prominence within the organisation in approximately the past five years.

²⁰⁴ Author's interview, Kintu E. Ivan, National Community of Women Living with HIV/AIDS (NACWOLA), 4 March 2010, Kampala, Uganda.

Internal dynamics including past personal and work experience of staff members, and the group's shifting focus over time have played important roles in altering the group's functions and emphasis, particularly in relation to advocacy and framing. Several people within NACWOLA headquarters previously worked with international development organisations such as the International Rescue Committee and CARE international, while others came with experience from government community action programmes, women's organisations, and broadcasting. The Director,²⁰⁵ arrived at NACWOLA having worked with international organisations and holding Master's degree in Development Studies. For at least one respondent a rights approach was not new when he joined NACWOLA. He commented, "many organisations that I've worked for they've been on rights, rights."²⁰⁶

Several respondents remarked on considerable change within the organisation in the recent past, including the shift from advocacy as a project to a core area of work, a move that has been accompanied by an increased in rights language. Around this time advocacy foci transitioned from programmatic advocacy based at the district level, to more issue- oriented and international advocacy. One respondent noted that although advocacy had always been an important and central area of work, this initiative was initially seen as seeking information and "has had a lot of faces,"²⁰⁷ only gradually becoming understood explicitly as advocacy. As advocacy become more clearly identified, so too did connections to rights. One respondent's description of the organisation's purpose mirrored this transition, beginning with support, and moving towards advocacy with some use of rights. He stated that NACWOLA exists to:

²⁰⁵ At the time of interviews.

²⁰⁶ Author's interview, Employee 2, National Community of Women Living with HIV/AIDS (NACWOLA), 20 March 2010, Kampala, Uganda

²⁰⁷ Author's interview, Kintu E. Ivan, National Community of Women Living with HIV/AIDS (NACWOLA), 4 March 2010, Kampala, Uganda.

support women living with HIV and AIDS so that the quality of their life is improved through better services, accessing better services, drugs and all those and also having psychosocial support, but very strongly to act as a voice for these women living with HIV/AIDS so that the services are able to be offered to them, so it's a question of advocacy and also promotion of their rights.²⁰⁸

While respondents exhibited familiarity with rights and paid real attention to these ideas in programming, particularly in reference to women's rights and children's rights, these ideas were not a super frame which shaped and explained the organisation's advocacy. Instead, as above, a series of approaches were mentioned when describing the organisation's work including development, poverty, gender and equity. While the specific words used varied by respondent, each person tended to give a list of key approaches with each one considered to hold approximately equivalent emphasis.

Within NACWOLA rights continue to exist as one approach among others but have clearly gained prominence over time. The director, who came to the organisation two years prior to the interviews, noted that the dominant approach when she arrived at NACWOLA differed significantly from current perspectives, stating:

when I joined, NACWOLA was using a sympathy kind of approach – saying these are HIV+ women and so they lacked the technical skills and this networking I'm talking about. So, what they would do is mobilise women around to maybe go and march on the street or something.²⁰⁹

Another respondent noted a gradual shift in emphasis from development to human rights within the organisation. Reflecting on the organisation's history, he noted, "when you trace how NACWOLA's been operating it wasn't featuring so much as a human rights organisation, a

²⁰⁸ Author's interview, Employee 2, National Community of Women Living with HIV/AIDS (NACWOLA), 20 March 2010, Kampala, Uganda.

²⁰⁹ Author's interview, Employee, National Community of Women Living with HIV/AIDS (NACWOLA), 29 March 2010, Kampala, Uganda.

human rights-oriented [group], no, I wouldn't say that."²¹⁰ He felt that he himself had pulled rights into the organisation after witnessing women with HIV being told they could not draw water from a common well or being given tubal ligation without consent, noting he had commented in relation to these events, "I think we have a question of human rights abuse for women living with HIV and AIDS."²¹¹ Internal organisational change, coming from personnel, their exposure to other groups, and leadership have shifted the nature of the organisation to be more advocacy-oriented and, in this context, to draw on rights as an additional tool.

5.1.3 Extra-organisational Factors Affecting Frame Selection

*"you cannot achieve your specific goal if you do it alone."*²¹²

5.1.3.1 Domestic Factors

Domestic factors including interaction with other groups through participation in coalitions and organisational niche among Ugandan civil society play a role in influencing frame selection and use. Born of necessity, domestic coalitions are an important component of NACWOLA's advocacy strategy and are also viewed as a platform for cross-fertilisation including exposure to new frames such as rights. Respondents frequently referred to coalition-based advocacy as essential for reasons of financing, commenting that "unfortunately advocacy does not bring in money, it is one of the poorest resourced departments that we have."²¹³ However, many felt that while coalitions may be formed out of financial necessity they were also the most successful strategy. Respondents reported that NACWOLA was part of the Civil Society Coalition on the HIV/AIDS Prevention Bill, the Consortium of Advocates for Anti-Retroviral Treatment

²¹⁰ Author's interview, Kintu E. Ivan, National Community of Women Living with HIV/AIDS (NACWOLA), 4 March 2010, Kampala, Uganda.

²¹¹ Author's interview, Kintu E. Ivan, National Community of Women Living with HIV/AIDS (NACWOLA), 4 March 2010, Kampala, Uganda.

²¹² Author's interview, Employee, National Community of Women Living with HIV/AIDS (NACWOLA), 29 March 2010, Kampala, Uganda.

²¹³ Author's interview, Employee, National Community of Women Living with HIV/AIDS (NACWOLA), 29 March 2010, Kampala, Uganda.

(CAAT), the Coalition Against TB (CATB), Monitoring, Transparency and Accountability of all Medicines (MeTA) and a stockout campaign coalition. These coalitions were described by several respondents as a nexus for the regular exchange of ideas including exposure to rights language. These coalitions served to expose NACWOLA to the use of rights in advocacy and to connect this terminology to particular issues and struggles, rather than adopt it as a broader worldview.

Within Uganda, NACWOLA respondents saw the group as holding a unique niche for a number of reasons, none of them related to the group's use of rights. Instead, respondents highlighted the group's focus on women and its female membership, while others focused on the HIV positive status of their members. One respondent noted the importance of the intersection of these two issues, commenting that while there are "a number of women[']s groups in Uganda that do a lot of other things and HIV is one of them. But for us, HIV is the whole picture."²¹⁴ As noted in organisational publications, respondents frequently commented that NACWOLA is "the only national organisation to bring together women living with HIV/AIDS."²¹⁵ This identity-based personnel, membership and niche was highlighted as a factor that made NACWOLA's advocacy fundamentally different from those conducted by other groups more distanced from the issues. One respondent stated:

Because our advocacy as [people living with HIV/AIDS] networks is different from if you stand up and start advocating for people living with HIV, you understand? So, for me, when I stand up I'm talking about myself as a person living with HIV.²¹⁶

²¹⁴ Author's interview, Kintu E. Ivan, National Community of Women Living with HIV/AIDS (NACWOLA), 4 March 2010, Kampala, Uganda.

²¹⁵ Author's interview, Kintu E. Ivan, National Community of Women Living with HIV/AIDS (NACWOLA), 4 March 2010, Kampala, Uganda.

²¹⁶ Author's interview, Employee, National Community of Women Living with HIV/AIDS (NACWOLA), 29 March 2010, Kampala, Uganda.

In contrast with rights, seen as a useful and important topic which applied to particular campaigns, the organisation's identity and niche as a group of HIV positive women served as the consistent starting point and key perspective in advocacy.

5.1.3.2 International Factors

International connections have played an important role in the group's inception, funding and development, including its origin as a female-oriented group, and increasing rights emphasis over time. As noted earlier, the organisation began after the founders attended an ICW conference in Amsterdam, with the conference playing a key role in inspiring the formation of the group. One respondent described the impact of these early international connections:

It was from the international connections that this organisation started. After these ladies attended the international conference of women living with HIV and AIDS organised by ICW they were funded by these organisations, and from there they saw a need to replicate the same thing down here [in Uganda]. So it is a very strong feature, maybe if that was not done at that level – it was a sort of eye opening – maybe these ladies would have been continually suffering....²¹⁷

At home in Uganda women faced a lot of questions and a lot of blame. One respondent commented that “at that time they were saying HIV is immoral so anybody who had HIV at that time was an immoral person” and the burden of this judgment fell primarily on women as “the men died first [and] it was always the women left behind and they had a lot of questions to answer.”²¹⁸ Ugandan women living with HIV lacked information and sought this out through the international conference.

²¹⁷ Author's interview, Kintu E. Ivan, National Community of Women Living with HIV/AIDS (NACWOLA), 4 March 2010, Kampala, Uganda.

²¹⁸ Author's interview, Kintu E. Ivan, National Community of Women Living with HIV/AIDS (NACWOLA), 4 March 2010, Kampala, Uganda.

Currently, NACWOLA headquarters has a moderate level of international connection, with the director travelling extensively and others at the programming level having periodic interaction with groups outside of the country. These connections were primarily cited by respondents as important in increasing access to funding, networking and learning about new advocacy techniques. The director noted, for example, that at her first international conference, the World AIDS Conference in Mexico she made contact with a series of international (Irish AID, USAID, UNAIDS) and domestic actors (AIDS Info Centre, Uganda AIDS Commission, Minister of Gender). She noted that World AIDS Conferences had also been useful in making connections with other networks of people living with HIV internationally, linkages that served to inform NACWOLA's advocacy strategy. The director noted, for example, that connecting with the Global Network of People Living with HIV (GNP+) and learning from their advocacy strategies was critical, commenting that she learned from them the importance of having numbers to back up arguments in advocacy. This prompted her to think about "engaging ... in strategic alliances"²¹⁹ internationally including recruiting volunteers from the US, UK, Germany and Canada to increase technical capacity. The group was described as having "good connections with very many other organisations outside of the country"²²⁰ with several respondents commenting on linkages with six partners organisations through Health Link, one of the organisations' donors. Interaction with these partner groups in Ethiopia, Kenya, Malawi and Zimbabwe was considered an important source of exchange. Meetings and communication with these groups involved joint proposals and activities (ie development of Monitoring and Evaluation tools) and the sharing of ideas and best practices such as sharing information through

²¹⁹ Author's interview, Employee, National Community of Women Living with HIV/AIDS (NACWOLA), 29 March 2010, Kampala, Uganda.

²²⁰ Author's interview, Employee 2, National Community of Women Living with HIV/AIDS (NACWOLA), 20 March 2010, Kampala, Uganda.

ICT (blogs, twitter) and new ideas such as advocacy through grandmothers (from the group in Kenya) and the idea of a child phone helpline (Zimbabwe).²²¹

Contemporary international interactions have also provided inroads for rights-based approaches, which are drawn on where they are thought to contribute to particular campaign topics. In some instances international connections have played a key role in advocacy framing. Several respondents, for example, noted that a volunteer from the UK brought with her significant expertise in the area of child rights, developing an organisational policy, and leading the organisation to expand its work in this area using an explicit rights frame. In this case, this influence significantly shifted the manner and degree to which the group worked on this issue, with child rights now an important area of work. Work on a draft bill addressing HIV prevention and control was also influenced by international connections, in this case South African, Canadian and regional (East African) linkages where expertise was specifically sought with respect to advocacy strategies and mechanisms and a rights-based approach. Respondents also noted that international meetings and conferences have been important in exposing the group to new advocacy strategies. For at least one individual, who now plays a key role with regards to advocacy within NACWOLA, initial exposure to human rights language also held an international link, describing an interaction with an Italian priest who wrote a citizen's handbook highlighting rights noting "[t]his is the guy who introduced me to the human rights concepts and I really loved them."²²²

²²¹ Author's interview, Employee 1, National Community of Women Living with HIV/AIDS (NACWOLA), 20 March 2010, Kampala, Uganda.

²²² Author's interview, Kintu E. Ivan, National Community of Women Living with HIV/AIDS (NACWOLA), 4 March 2010, Kampala, Uganda.

5.1.3.3 Donors

As with many organisations international donors were critical sources of organisational funding, with one respondent noting, “the bigger part of our funding, all these 20 years has not been coming from the local, it has been coming from abroad.”²²³ In the early years, the United Nations Development Program (UNDP) was an important funder with their funding “g[iving] recognition and [then] money started coming in.”²²⁴ The Norwegian Council for Africa was also cited as an important early funder, supporting capacity building within the organisation for almost ten years and encouraging the group to involve men as well as women. Other donors have included²²⁵ the UK’s DFID, Interact Worldwide UK, Comic Relief, Health Link UK, World Food Program, Save the Children Uganda, United Nations Fund for Women, the Peace Corps, African Development Fund for Women, Volunteer Service Overseas, Gtz: German Technical Cooperation, United States Agency for International Development (USAID), Management Science for Health, and John Snow International. These donors represent a mix of rights-oriented and non-rights oriented funders, including several with specific topic or constituency foci (ie women, children, nutrition). When asked about donor impressions towards particular frames or approaches it was noted that “donors are using the rights based approach as a centre” and “many donors want to fund human rights, generally.”²²⁶ Respondents noted in the last few years donors had begun coming to NACWOLA having been recommended by other donors, or having witnessed NACWOLA’s activities.

²²³ Author’s interview, Kintu E. Ivan, National Community of Women Living with HIV/AIDS (NACWOLA), 4 March 2010, Kampala, Uganda.

²²⁴ Author’s interview, Kintu E. Ivan, National Community of Women Living with HIV/AIDS (NACWOLA), 4 March 2010, Kampala, Uganda.

²²⁵ As listed in publications and in interviews

²²⁶ Ie not specifically linked to HIV. Author’s interview, Kintu E. Ivan, National Community of Women Living with HIV/AIDS (NACWOLA), 4 March 2010, Kampala, Uganda.

5.1.4 Impact

“as much as there has been a lot of discussion, a lot of awareness raising on rights, some people still do not respect the rights.”²²⁷

The selection of an advocacy frame was seldom clearly linked by respondents to perceptions of impact. Instead, respondents indicated that frames were chosen depending on their fit with the particular subject of each campaign. Rights were understood as a topic that aligned with some issues but not with others and, as such, would be drawn upon only when called for. While the concept of rights was thought to be understood locally, respondents noted occasional conflicts between rights and local cultural practices. Women, children and those living with HIV, the constituencies that NACWOLA specifically represents and works for, were singled out as having “their rights trampled upon.”²²⁸

NACWOLA’s primary orientation and identification is that of an organisation by and for women, however, rights are one of several frames that are drawn on and used in advocacy, where they are seen to have a direct relevance with the issue at hand. In interviews respondents made primary reference to two recent areas of advocacy, both in which rights language played a role: 1) Children’s Rights, and 2) the Draft HIV/AIDS Prevention and Control Bill.

5.1.4.1 Campaigns

5.1.4.1.1 Children’s Rights

NACWOLA’s work on children was highlighted in multiple interviews. Respondents noted that work in this area came about organically as they worked with women and their families, often retaining a connection with children after their mothers had passed away. One respondent noted

²²⁷ Author’s interview, Employee 2, National Community of Women Living with HIV/AIDS (NACWOLA), 20 March 2010, Kampala, Uganda.

²²⁸ Author’s interview, Employee 2, National Community of Women Living with HIV/AIDS (NACWOLA), 20 March 2010, Kampala, Uganda.

that some of these children “see NACWOLA as their mother.”²²⁹ One campaign in this area was work towards a government policy on Orphans and Vulnerable Children (OVCs). Respondents noted that “there was no policy guiding action and rights were being abused” and that NACWOLA was “instrumental in bringing this into place.”²³⁰ NACWOLA respondents described the project as emerging from memory work,²³¹ a process which often facilitated or led to disclosure of HIV status. This process served to “bridg[e] a communication gap between parents, children and guardians’ succession planning.”²³² Witnessing the impact of disclosure and the difficult issues faced by children who lost their parents, NACWOLA approached the Ministry of Gender, a ministry also responsible for youth and children. They noted that the country had an HIV policy but no OVC policy. At the time, approximately two years prior to the interview, respondents described Uganda as “the darling everywhere” with reference to HIV interventions, and, as a result, anything relating to HIV had high political visibility, with politicians not “want[ing] issues to pop up.”²³³ This “success story” paradigm was the point of reference, and the group was able to leverage that effectively. Work on children was also seen as an accessible topic, where there was both a need and available funding. Respondents, while seeing the organisation’s contribution as important, did not view the intervention as an unqualified success noting, “I don’t want to say [the policy] is well implemented but at least there’s a framework.”²³⁴

²²⁹ Author’s interview, Kintu E. Ivan, National Community of Women Living with HIV/AIDS (NACWOLA), 4 March 2010, Kampala, Uganda.

²³⁰ Author’s interview, Kintu E. Ivan, National Community of Women Living with HIV/AIDS (NACWOLA), 4 March 2010, Kampala, Uganda.

²³¹ For example, memory books which help children who have lost their parents remember them.

²³² Author’s interview, Kintu E. Ivan, National Community of Women Living with HIV/AIDS (NACWOLA), 4 March 2010, Kampala, Uganda.

²³³ Author’s interview, Kintu E. Ivan, National Community of Women Living with HIV/AIDS (NACWOLA), 4 March 2010, Kampala, Uganda.

²³⁴ Author’s interview, Kintu E. Ivan, National Community of Women Living with HIV/AIDS (NACWOLA), 4 March 2010, Kampala, Uganda.

Work on children more broadly was identified by several respondents as a key area of NACWOLA intervention, with each citing a common source for this area of work and its rights-based orientation. As one respondent commented, “a lady from the UK was very instrumental in creating a child protection policy for the organisation which is now at an advanced stage.”²³⁵ Respondents noted that both the area of work and the rights frame were introduced by the international volunteer. The group now is involved in child rights advocacy as well as leading training workshops for other groups. One respondent noted “we advocate for children’s rights to be observed at the organisational level and at the community level.”²³⁶ Children’s rights were cited as a major area of advocacy, and as a transformation approach, with the idea of children’s rights being a relatively new and unfamiliar idea. One respondent noted, that “child abuse is linked to a lack of knowledge around children’s rights,” noting that 38% of children experience violence.²³⁷

While this campaign was explicitly formulated within a rights frame, respondents noted some local challenges in utilising this frame effectively, particularly referencing cultural obstacles. One respondent noted that while, “people understand, people react to, [and] leaders they value” rights, “sometimes those rights are in conflict with our culture.”²³⁸ A gap between knowledge and practice was also highlighted, with one respondent commenting that although participants

²³⁵ Author’s interview, Employee 2, National Community of Women Living with HIV/AIDS (NACWOLA), 20 March 2010, Kampala, Uganda.

²³⁶ Author’s interview, Employee 2, National Community of Women Living with HIV/AIDS (NACWOLA), 20 March 2010, Kampala, Uganda.

²³⁷ Author’s interview, Employee 2, National Community of Women Living with HIV/AIDS (NACWOLA), 20 March 2010, Kampala, Uganda.

²³⁸ Author’s interview, Employee 2, National Community of Women Living with HIV/AIDS (NACWOLA), 20 March 2010, Kampala, Uganda.

may “list a full flipchart” of rights in workshops, with reference to children’s rights, “on the ground you’ll find only 5% are respected.”²³⁹

5.1.4.1.2 Draft HIV/AIDS Prevention and Control Bill

A high profile campaign at the time of research focused on the draft national HIV/AIDS Prevention and Control Bill. Aimed at containing and reducing infection, the bill was an epidemiologically-oriented piece of proposed legislation targeting the virus but, in NACWOLA’s view, neglecting key human rights concerns, including the human context of the virus’ existence and spread. The bill held provisions allowing medical personnel to disclose HIV status to anyone whom they felt could be at risk of infection, laid out provisions for HIV Testing, and provided for the death penalty for anyone who willfully infects another. NACWOLA campaigned for revisions to this bill in conjunction with a 19-member domestic NGO coalition which prepared and presented a joint civil society statement. The statement had a strong human rights emphasis, with human rights appearing three times in the table of contents alone, and the foreword written by the Uganda Network on Ethics, Law and HIV/AIDS, an organisation with an explicit and dominant rights approach.

From NACWOLA’s perspective, their organisational approach to the campaign featured two main frames: human rights and gender. The human rights emphasis was explained primarily in relation to the draft bill’s criminalisation, and the proposal of punitive measures in a context of inadequate access to services. One respondent elaborated:

²³⁹ Author’s interview, Employee 2, National Community of Women Living with HIV/AIDS (NACWOLA), 20 March 2010, Kampala, Uganda.

When you criminalise, when you are picking out a person, first of all you are discriminating isn't it? That is a serious violation of rights and secondly, why we picked it as people living with HIV as a right issue is that, much as government is putting blame on people living with HIV, there is no access to services. There [is] no access to drugs and for us a provision of health services and access is actually a human rights issue. It's really my right to have the medicine provided to me by the government, you understand... And then also really to say that when you infect somebody and even yet there are no mechanisms in place to know who has infected the other and then you say that it will be a death penalty I think to that extent – it's really kind a rights issue.²⁴⁰

Here criminalisation is portrayed as a form of victimisation. It entails identifying vulnerable people and placing the blame on them, in a setting where blame may be somewhat arbitrarily assigned as most people do not know the exact circumstances of their infection. There is also a suggested conflict of rights and prioritisation, with blame and criminal consequences being placed on those infected, while access to the services that could reduce infectiousness, an onus described here as falling on the government, is inadequate. Rights issues were also identified by NACWOLA with respect to disclosure, as “all the rights of a person living with HIV were transferred to the medical person,” by giving medical personnel “the right to disclose my status to anybody when that a doctor feels is at risk.”²⁴¹ This phraseology suggests that medical personnel are almost seen as proxy rights bearers in this situation with people living with HIV implicitly seen as not able or willing to exercise their rights in line with the draft bill's aims.

NACWOLA's gender emphasis in this campaign is closely linked to the bill's focus on people living with HIV and closely aligns with the arguments presented earlier regarding singling out a particularly vulnerable group for blame rather than assistance. One respondent elaborated:

²⁴⁰ Author's interview, Employee, National Community of Women Living with HIV/AIDS (NACWOLA), 29 March 2010, Kampala, Uganda.

²⁴¹ Author's interview, Employee, National Community of Women Living with HIV/AIDS (NACWOLA), 29 March 2010, Kampala, Uganda.

[W]hen you look at the content of the bill you would see that the bill was basically focussing on people living with HIV – you know, putting the whole blame and the whole burden on people living with HIV... When you want to put a burden on someone living with HIV it means that 70%... we feel that it's about 70% of the whole HIV burden it's actually on the women from care giving, to carrying the child who is HIV positive, to being HIV positive yourself, to providing for the family for food... So that is why for me in that particular bill I picked out those two elements really as a gender and a human rights issue.²⁴²

With regards to the selection of frame, both rights and gender are given factual justification. Rights is explained as an approach due to the existence of rights violations in the form of discrimination and gender due to the over-representation of women among those living with HIV/AIDS. In this campaign it was also noted that the organisation's experiential expertise played an important role, with one respondent noting that the organisation's Director had spoken in parliament about the implications the bill would have on her life if passed, with the respondent noting that having a woman living with HIV speak in parliament is different than "having some male professor come in and talk statistics."²⁴³

Working with other NGOs was highlighted as critical in this campaign, including the coalition of domestic NGOs noted earlier. Described as a "very huge advocacy initiative that has people living with HIV greatly involved,"²⁴⁴ advocacy on this campaign involved learning across sectors, and consultation with groups such as the Uganda Human Rights Commission. International connections were considered particularly important in contributing substantively to the campaign, especially in the area of rights. South Africa's Treatment Action Campaign was contacted and asked to share any HIV/AIDS laws that they were familiar with, sending the

²⁴² Author's interview, Employee, National Community of Women Living with HIV/AIDS (NACWOLA), 29 March 2010, Kampala, Uganda.

²⁴³ Author's interview, Maya Bertsch, National Community of Women Living with HIV/AIDS (NACWOLA), 25 March 2010, Kampala Uganda.

²⁴⁴ Author's interview, Employee, National Community of Women Living with HIV/AIDS (NACWOLA), 29 March 2010, Kampala, Uganda.

SADC model law (SADC Parliamentary Forum 2008) which emphasises a human rights approach. NACWOLA personnel studied the SADC model law and compared it to the proposed Ugandan bill commenting that “we realised that ours was like the opposite.”²⁴⁵ As a result of seeing the other bill NACWOLA was “able to actually analyse the issues of human rights or protection of all this gender issues and all that” and to have a “position and ... understanding” when they went to meet MPs.²⁴⁶ The Canadian HIV/AIDS Legal network was also cited as a critical source, upon request sending “information of related cases and issues of criminalisation.”²⁴⁷ These external sources of information and support were considered very important, particularly in the face of strong opposition from Ugandan MPs, with the Canadian HIV/AIDS Legal Network assisting NACWOLA in drafting a letter to the UN Special Rapporteur on Human Rights on the matter. The submission to the UN Special Rapporteur was noted as, “one of the reasons I am sure why the HIV/AIDS Bill is quiet now” indicating that the letter was forwarded by the Special Rapporteur to government. As of January 2012 there had been no further movement with the bill, with NACWOLA noting “[t]he delayed process of having the bill passed/discussed is one success that we are proud of.”²⁴⁸ NACWOLA and the coalition also used expertise gained through this campaign to contribute to dialogue around the creation of an East African regional bill on HIV, where they have “linked up” with regional groups ensuring that “when we had all these meetings [with government] on the bill we had a common consensus.”²⁴⁹

²⁴⁵ Author’s interview, Employee, National Community of Women Living with HIV/AIDS (NACWOLA), 29 March 2010, Kampala, Uganda.

²⁴⁶ Author’s interview, Employee, National Community of Women Living with HIV/AIDS (NACWOLA), 29 March 2010, Kampala, Uganda.

²⁴⁷ Author’s interview, Employee, National Community of Women Living with HIV/AIDS (NACWOLA), 29 March 2010, Kampala, Uganda.

²⁴⁸ Personal correspondence with Employee, 13 January 2012.

²⁴⁹ Author’s interview, Employee, National Community of Women Living with HIV/AIDS (NACWOLA), 29 March 2010, Kampala, Uganda.

NACWOLA's involvement in campaign on the HIV/AIDS Prevention and Control Bill indicates a two-pronged approach with regards to frame, with emphasis placed on both rights and gender. While both of these played a critical role and were linked to outcomes, the connection was reflected in interviews as indirect. Linking with other groups, which was done primarily through the rights frame, was seen as a critical advocacy strategy. This strategy enabled access to comparative information, and to mechanisms, such as the Special Rapporteur on the Right to Health, through which NACWOLA was able to get the ear of government in a new way. Gender was reported as critical as a strategy because of the disproportionate impact on women, but was seen as effective because, in the form of the director, it enabled NACWOLA to speak directly and personally, rather than theoretically, about the potential impact of the bill.

5.1.5 Conclusions: NACWOLA

NACWOLA is an organisation that is familiar with and readily uses rights as one tool among others with which to achieve their aims. This group demonstrates a selective but growing use of the rights frame alongside frames of gender and development. Internal factors such as changes in personnel appear to have played an important role in this shift, with a more rights oriented leadership, an advocacy officer with a rights perspective, and a re-organisation placing increased emphasis on both advocacy and rights. External factors have also been influential. A volunteer from the UK initiated work on child rights, an ongoing area of work which has retained a rights frame. Domestic coalitions have also encouraged a rights-based advocacy by placing NACWOLA alongside rights-oriented groups who have helped NACWOLA to increase their knowledge of and utilisation of this frame. Rights are not, however, a dominant frame and are understood within the group as an important topic rather than an organisational ethos. The group

tends to choose frames on a campaign by campaign basis, selecting the frame that they view as emerging from a particular topic.

Reflecting on the hypotheses, as an organisation reflecting a shift toward rights, NACWOLA indicates some support for explanations that highlight the influence of leadership and external actors. These influences are, however, mitigated by organisational structure and by the group's strong membership-based identity. As a decentralised membership-based organisation the group's constituency of HIV positive women remains central to the group's advocacy approach, identity and niche. In NACWOLA's offices across Uganda, living with HIV is a shared experience and one that defines the organisation. NACWOLA's external exposure to rights through domestic networks and international connections have resulted in the uptake of rights for specific campaigns, however, these interactions have not resulted in the group taking on rights as a dominant frame.

Above all, NACWOLA's organisational identity continues to be based primarily on being a group of and for HIV positive women. This niche holds strong personal meaning for members, makes the group relatively unique in Uganda, and provides NACWOLA with a specific advocacy voice grounded in the experience of its constituency. NACWOLA does not support hypotheses which link frame choice to perceptions of impact at either the policy or individual level. Instead, respondents highlighted the unique character of NACWOLA advocacy as advocacy conducted by the group of people (HIV positive women) they represent.

5.2 Southern African HIV and AIDS Dissemination Service (SAfAIDS)

*“HIV Information: The Power to Make a Difference”*²⁵⁰

Founded with the objective of creating and disseminating information in order to enable community-level action, SAfAIDS is an organisation that operates primarily, but not exclusively within a development frame, drawing on rights in particular contexts and on specific topics. A regional organisation with operations throughout Southern Africa, the group emphasises different perspectives on particular campaigns, with rights appearing primarily in the context of gender in relation to violence against women. SAfAIDS respondents viewed their role as providing information and facilitating dialogue understanding these as the most important features of their advocacy work, and ones which overshadow the idea of frame selection. The group considers itself to hold chiefly a ‘behind the scenes’ role in facilitating and supporting their partners to advocate openly.

As a case SAfAIDS highlights some of the same factors and hypotheses as NACWOLA while also illustrating some important differences. In contrast with NACWOLA, intra-organisational factors including leadership and personal experience were not widely cited with reference to frame selection and use either generally or in reference to rights more specifically. Like NACWOLA, extra-organisational factors such as regional context and advocacy norms, and organisational niche were important influences, but in SAfAIDS’ case mainly with regards to advocacy methods or approach rather than frame. As with NACWOLA perceptions of impact were not linked to frame, but, in this instance were related to the methods of advocacy with an emphasis on the importance of participatory approaches.

²⁵⁰ SAfAIDS Website – Home Page, 2012.

5.2.1 Frame

*I think the overarching approach for us is we address HIV from a development perspective. For us it's a development and a human rights issue, those two approaches from a human rights perspective and from a development perspective*²⁵¹

SAfAIDS defines itself primarily as an organisation that exists to produce and disseminate materials on HIV, with varying emphasis placed on frames of development and rights. Development is given primacy in several key organisational documents. The group's mission, frames SAfAIDS' "HIV and AIDS knowledge management, capacity development, advocacy, policy analysis and documentation" as holding the objective of "promot[ing] effective and ethical development responses" to the pandemic. SAfAIDS' guiding principles note the group exists to "[p]romote understanding, analysis, and focus on the critical impact of HIV and AIDS as a development issue rather than simply as a health issue" bolding this phrase on their website to highlight its significance (SAfAIDS website – About us, 2012). Development is referenced three times in these guiding principles which also emphasise the need for a multi-sectoral response, alignment with national responses, involvement of people living with the virus, quality information, and gender mainstreaming (SAfAIDS website – About us, 2012). The organisation's vision notes "the needs of communities" as the motivating force behind the group's work, while other documents include rights as an important organisational concept (SAfAIDS website- About us, 2012). The values said to "guide" SAfAIDS' work include "justice and equity" and "respect for diversity and human rights" while the website's

²⁵¹ Author's interview, Employee 1, Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), 12 August 2010, Pretoria, Gauteng, South Africa.

areas of focus include two specific rights references (Human Rights, and Sexual Reproductive Health and Rights) in a list of nine topics (SAfAIDS website – About us, 2012).²⁵²

The more than 60 materials displayed and observed at the SAfAIDS regional office indicate messaging drawing on a variety of frames.²⁵³ Main campaigns included one promoting adherence to the Abuja Declaration’s commitment of 15% of the budget to health (African Union 2001), World Cup-themed prevention messages²⁵⁴ often using the tag “Africa Wins Every Time you Prevent HIV” (SAfAIDS 2009b), some child-oriented prevention materials, a series of anti-stigma posters using the slogan “don’t be negative about being positive” and a variety of gender oriented materials, some addressing maternal mortality. Rights appeared on a poster promoting the ‘Changing the River’s Flow’ campaign which stated, “I enjoy supporting my partner and promoting her rights ... do you?” (SAfAIDS 2009a). They were also evident among three of six priority areas listed in a display under the heading “SAfAIDS Journey” one addressing women’s rights, one reproductive health, and the other the rights of those “living and affected by HIV and LGBTI.”²⁵⁵ Other priority areas emphasised prevention, a “family centred” approach incorporating reproductive health, best practices and research, and a “multilayered” approach to HIV and climate change (SAfAIDS n.d.).

Reflecting this diversity of approaches, respondents tended to list more than one frame, often including rights but with development the most prominent. One respondent chose policy and law

²⁵²Other topics are: gender, HIV prevention, HIV treatment, HIV care, HIV support, Lesbians, Gays, Bisexuals and Transgender, Orphans and Vulnerable Children (SAfAIDS Website, areas of focus).

²⁵³All materials observed in August 2010. A listing of all materials observed is included in Appendix B.

²⁵⁴Tying in with the 2010 World Cup held in South Africa.

²⁵⁵Priority area 2 (Gender Equality and Women’s Rights) states “promote gender equality and women’s rights to address HIV, GBV [gender-based violence], culture and women’s rights by confronting cultural practices, beliefs and customary laws that marginalise women and girls in Southern Africa – Changing the River’s Flow”

as the primary approach, noting “[w]e also deal with women’s rights, gender, women’s rights issues and community development,” further adding environmental issues.²⁵⁶ A second respondent felt that SAfAIDS had two dominant frames, development and human rights, but gave development slightly more emphasis, noting “so for us we address HIV from a development perspective.”²⁵⁷ Finally, the third respondent at different points in the interview listed development, gender and public health (in that order), or development and public health as being frames of equal importance within the organisation. She also mentioned women’s rights, culture and poverty in her elaboration of the application of these frames.

5.2.2 Extra-Organisational Factors Affecting Frame Selection

“The discussions are led by the community members themselves.”²⁵⁸

As a regional group working extensively with partners, and operating in diverse cultural contexts across ten countries, SAfAIDS is affected by a number of factors within and outside of the region which have an impact on its selection of frame. The organisation is heavily influenced by and responsive to regional cultural norms, understands itself as holding a unique niche in relation to other regional and national groups working on HIV and has a variety of donors, mostly from outside of the region, who operate with a variety of frames.

At the regional level, cultural norms emphasising consultation and dialogue are heavily influential on the manner in which SAfAIDS operates, fitting in with a capacity building and

²⁵⁶ Author’s interview, Employee 2, Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), 12 August 2010, Pretoria, Gauteng, South Africa.

²⁵⁷ Author’s interview, Employee 1, Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), 12 August 2010, Pretoria, Gauteng, South Africa.

²⁵⁸ Author’s interview, Employee 2, Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), 12 August 2010, Pretoria, Gauteng, South Africa.

development-oriented approach. Traditional leaders considered cultural custodians are important in several stages of community dialogues, with local chiefs leading the process in several areas. Respondents emphasised that while they facilitate dialogue and bring information, they seek for the communities themselves to determine areas of emphasis and the way forward.

We work through the organisations that are based within that community. SAFAIDS will just go, when the organisation requests that SAFAIDS come in just to witness our discussion; or just come in and address; or just come in and give guidance or information on the issue of HIV and AIDS. On the issue of cultural practices we don't say we know. We don't know. We are just neutral when we go to the community. It's led. The discussions are led by the community members themselves.²⁵⁹

Some cultural factors that were emphasised included consensus-based decision making, employing a non-confrontational approach, and an emphasis on a participatory and dialogue-based model. These techniques were given more weight than frames in interviews, though the process of dialogues was sometimes understood as a component of a development approach.

Similar themes were highlighted when respondents compared and contrasted their organisation to others working in the same or related fields. When distinguishing their organisation from others, respondents highlighted capacity building as SAfAIDS key, and often behind the scenes, role. Another respondent saw the group's niche as linked to its ability to draw on and employ a variety of frames, noting with reference to campaigns addressing gender, domestic violence and HIV:

²⁵⁹ Author's interview, Employee 2, Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), 12 August 2010, Pretoria, Gauteng, South Africa.

you will find that one organisation is focusing on culture alone; another gender-based violence or another on women's rights alone; another on HIV and AIDS alone. But for [SAfAIDS' campaign] it's all at once. We're joining them together.²⁶⁰

Respondents also noted that SAfAIDS stood out for its role as a “conduit” to bring “international issues to the region” and to “bring ... the issues happening here at a country level” to international fora.²⁶¹

As their conduit role suggests, SAfAIDS is an organisation with a high level of interconnectedness both inside and outside of the region. Operating using a partnership model within the region of Southern Africa, the group has extensive connections with domestic and community-based organisations as well as with regional and continental groups such as the Institute for Democracy in Africa (IDASA), the African Civil Society Coalition on Health, the African regional Public Health Alliance, the Pan-African Treatment Access Movement (PATAM), the cross-cultural regional black forum, and the AIDS and Rights Alliance for Southern Africa (ARASA). These settings were often reported to be settings where ideas and best practices were shared, with one respondent noting “[w]e share the different ideas of how we do things with these other international organisations”²⁶² including collaboration in book form, and a conference dialogue that continued through a magazine. These fora were not noted, however, for having an impact on selection of frame.

²⁶⁰ Author's interview, Employee 3, Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), 26 August 2010, Pretoria, Gauteng, South Africa.

²⁶¹ Author's interview, Employee 1, Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), 12 August 2010, Pretoria, Gauteng, South Africa.

²⁶² Author's interview, Employee 3, Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), 26 August 2010, Pretoria, Gauteng, South Africa.

SAfAIDS donors are primarily from outside of the region. Key donors listed in documentation include: the UK's Department for International Development (DFID), Humanist Institute for Development Cooperation (HIVOS, Netherlands), Irish Aid, Oxfam Canada, Canadian International Development Agency (CIDA), Swedish International Development Cooperation (SIDA), and UNAIDS. These donors represent a mix of approaches, with HIVOS, Irish Aid, and SIDA having overt human rights emphasis in their key areas of work, Oxfam Canada²⁶³ (Oxfam Canada website, 2012) and UNAIDS²⁶⁴ (UNAIDS website 2012) making some reference to rights, and CIDA (CIDA website – About CIDA, 2012 and DFID (DFID website – What we Do, 2012) making no reference to rights in their list of priority areas.

5.2.3 Impact

*“We produce information to produce advocacy.”*²⁶⁵

Views about impact among SAfAIDS respondents were linked primarily to process, again highlighting consultation, and secondarily to frame. Perspectives from within the organisation reflected the view that information and dialogue was often what was lacking in addressing social problems relating to HIV. As such, providing information and facilitating dialogue was heavily emphasised and believed to be the path to results. Respondents noted that, in this facilitation role, they tended to take a background role, noting, “we are working from behind to support them” elaborating “I think our role is to produce information for advocacy to happen, to

²⁶³While rights are not listed as a key program issue, one current slogan under poverty alleviation is “ending poverty poverty begins with women's rights” See: www.oxfam.ca/what-we-do/themes-and-issues (Accessed April 12, 2012).

²⁶⁴UNAIDS does not have a clear list of priorities for areas of funding, but does have a “Prevention, Vulnerability and Rights” Division. See: www.unaids.org/en/ (Accessed April 12, 2012).

²⁶⁵Author's interview, Employee 1, Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), 12 August 2010, Pretoria, Gauteng, South Africa.

facilitate advocacy.”²⁶⁶ In line with this perspective, comments about advocacy effectiveness tended not to be linked to rhetorical frame but to specific techniques of implementation. One respondent, for example, highlighted the importance of networking for advocacy to have an impact, noting SAfAIDS “need[s] a network of support, we also need an audience for our materials, for our messages, and we need to influence what’s happening at those levels.”²⁶⁷

Information production was highlighted as key not only for its contents, but also for the manner in which the information could be presented in advocacy. One respondent also described the organisation as having a unique niche contrasting the more dispassionate advocacy that they do with that of the networks of people living with HIV/AIDS that they work with. She stated:

The people living with HIV are generally emotional in their approach to advocacy such that they would want to demonstrate. When they present their issues, of course they are affected by issues. Therefore, when they are affected by something you know sometimes you become emotional about things. But for us we’ve realised that there’s really important issues that they need to discuss with the policymakers. At times that emotion makes it difficult for dialogue to take place. Therefore, we promote dialogue as a means or as a policy transformative tool.²⁶⁸

Dialogue, facilitation and information received the greatest attention from respondents, with these ‘how’ elements of the process of advocacy considered the most important factors in achieving the desired impact.

Even while process was emphasised over frame, rights were mentioned with relative frequency with reference to women’s rights and were raised almost exclusively in this context.

²⁶⁶ Author’s interview, Employee 1, Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), 12 August 2010, Pretoria, Gauteng, South Africa.

²⁶⁷ Author’s interview, Employee 2, Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), 12 August 2010, Pretoria, Gauteng, South Africa

²⁶⁸ Author’s interview, Employee 3, Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), 26 August 2010, Pretoria, Gauteng, South Africa.

Interestingly, rights were also seen as the most controversial in relation to gender, and this topic was noted as the area where they encountered frequent challenges and sensitivities regarding the use of rights.

When you talk about women's rights they will feel that we undermine men or men don't have rights. So when we talk about the rights itself, we approach it from the international human rights perspective. When you talk about the human rights you will just refer [to it] like: a woman is a human being and a man is a human being. A woman has got the right to reproductive health like in the human rights whereby a man has also got the right to reproductive health. You don't just emphasise on the part of a woman. Woman. Woman. Otherwise you won't get the buy-in from men.²⁶⁹

Rights were seen as a concept that people may have questions about and may be uncomfortable. Interestingly, the international human rights perspective was seen as less threatening than more localised conceptions of women's rights. Rights were also seen as linked with responsibilities, in ways that sometimes had complex gender implications. One respondent noted that while “unlocking that locked door in women's minds to say we have the rights on this and this and this” must also go along with expected consequences and behaviours noting “You need to be responsible as well.”²⁷⁰

5.2.3.1 Campaigns

SAfAIDS respondents emphasise that dialogue, facilitation and information are the cornerstones of their organisation and that they draw on diverse frames. What does this look like in practice and how do their campaigns fare? These questions will be examined with reference to two recent advocacy initiatives: 1) Changing the River's Flow, and 2) Policy Dialogues.

²⁶⁹ Author's interview, Employee 3, Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), 26 August 2010, Pretoria, Gauteng, South Africa.

²⁷⁰ Author's interview, Employee 3, Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), 26 August 2010, Pretoria, Gauteng, South Africa.

5.2.3.1.1 Changing the River's Flow

Initiated in 2006 with a pilot project in Zimbabwe, Changing the River's Flow has since been implemented in nine countries. Its stated goal is to “confront [...] cultural practices, beliefs and customary laws to promote gender equality and prevent gender-based violence (GBV) against women and girls in southern Africa” (SAfAIDS website – Changing the Rivers Flow, 2012) The project's five objectives are to: 1) “[s]trengthen the capacity of GBV organisations in southern Africa to address GBV and its linkages to culture, women's rights and HIV,” 2) enable communities to “redress gender inequalities to reduce GBV through community driven strategies,” 3) “[s]trengthen advocacy and monitoring initiatives that will influence policy and practice on gender equality and gender-based violence at regional, national and community level,” and “[d]ocument and share community best practices that challenge gender dynamics in a cultural context to address GBV” (SAfAIDS website – Changing the River's Flow, 2012). Posters, and the weblink relating to this initiative carry the phrase “changing gender dynamics in a cultural context to address HIV” while the poster also features the slogan “I enjoy supporting my partner and promoting her rights ... do you?” (SAfAIDS website – Changing the River's Flow, 2012, SAfAIDS, n.d.).

In interviews respondents described this project as “basically an issue of culture, women's rights and gender-based violence in relation to HIV and AIDS” adding that “[a]s much as we have different partners in each country, it's our project ... it's SAfAIDS' thing.”²⁷¹ Respondents in this case agreed that while usually “behind” the scenes in advocacy in this case they were “in

²⁷¹ Author's interview, Employee 2, Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), 12 August 2010, Pretoria, Gauteng, South Africa.

front.”²⁷² Two out of three respondents directly referenced women’s rights when describing the campaign, noting the campaign consisted of “advocating for women’s rights to be integrated in the HIV and AIDS prevention” and for “women’s rights as a way of redressing the gender-based violence within the communities or within the societies.”²⁷³ Culture was also heavily emphasised, however, with one respondent commenting that while it addressed “[w]omen’s rights, gender-based violence basically, and culture ... [t]he most important thing is culture.”²⁷⁴ The third respondent situated the campaign solely within the cultural frame.

The project aims primarily at shifting community attitudes and practices and is dialogue-centred. The program entails SAfAIDS training participating organisations, who, in turn, train community-based volunteers. The focus is on community dialogues which entail illuminating linkages between the spread of HIV, women’s rights and cultural practices. Community-based volunteers broach discussions, asking, for example about cultural practices that may have implications for HIV. Traditional leaders are involved from the outset understood as “the custodians of culture”²⁷⁵ and once dialogues begin are “there in front leading the discussion.”²⁷⁶ SAfAIDS does not enter into dialogues with a predetermined outcome instead stating “the community defines their own outcomes.”²⁷⁷ One respondent elaborated:

²⁷² Author’s interview, Employee 2, Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), 12 August 2010, Pretoria, Gauteng, South Africa.

²⁷³ Author’s interview, Employee 3, Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), 26 August 2010, Pretoria, Gauteng, South Africa.

²⁷⁴ Author’s interview, Employee 2, Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), 12 August 2010, Pretoria, Gauteng, South Africa.

²⁷⁵ Author’s interview, Employee 3, Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), 26 August 2010, Pretoria, Gauteng, South Africa.

²⁷⁶ Author’s interview, Employee 1, Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), 12 August 2010, Pretoria, Gauteng, South Africa.

²⁷⁷ Author’s interview, Employee 1, Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), 12 August 2010, Pretoria, Gauteng, South Africa.

So we're looking at both positive and negative cultural practices and [we don't] say "I would do this", no. We're going to the community and saying, "what are the cultural practices in this community?" People talk about everything: men on their own; women on their own; youth on their own. Then they say, "do you think there is a relationship between HIV and these practices in this community?" Then people discuss.²⁷⁸

Facilitators will then "give them information so they have understanding of the spread of HIV and AIDS, the mode of transmission," while the community itself "are the ones who will say oh, now we see!"²⁷⁹ and develop a way forward. As such, while the campaign itself has a slogan, beyond the general objective of changing cultural attitudes and practices around gender to prevent HIV, there is not a specific SAfAIDS-directed goal, as the details vary by location and community perspective.

In Seke, Zimbabwe, respondents mentioned a dialogue that addressed the issue of wife inheritance,²⁸⁰ noting that chiefs strongly stated that it was an integral part of their culture and women in the community appeared to support inheritance. SAfAIDS personnel "d[id] not condemn"²⁸¹ the practice, instead fostering a series of dialogues about HIV transmission. One respondent described the process:

[I]nitially the chiefs said "no, no, no, we cannot change wife inheritance. It is our culture." But it is only in the very last community dialogue where he said, "hah! You know what you have said now. Now there's this HIV what do we need to do?" But you know like he was hanging onto his culture which we didn't say is wrong.²⁸²

²⁷⁸ Author's interview, Employee 1, Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), 12 August 2010, Pretoria, Gauteng, South Africa.

²⁷⁹ Author's interview, Employee 3, Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), 26 August 2010, Pretoria, Gauteng, South Africa.

²⁸⁰ Where after her husband's death a woman is inherited, usually by her husband's brother.

²⁸¹ Author's interview, Employee 1, Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), 12 August 2010, Pretoria, Gauteng, South Africa.

²⁸² Author's interview, Employee 1, Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), 12 August 2010, Pretoria, Gauteng, South Africa.

The community brainstormed, developing a new community practice that prior to a wife inheritance both parties would be tested for HIV at the clinic, a solution that was endorsed by the chiefs.

Respondents reflected on the project's name noting that it was 'changing the river's flow' and that "[w]e are not looking to stop the river's flow"²⁸³ but to change its course, to cause it to "meander"²⁸⁴ in a different direction. The project's report noted that the name for the project "mirrors the idea that culture is not fixed, like a rock or stone but that, it is a 'river,' constantly moving and changing" and that it is "something beautiful, rich and vital for our lives, just as a river is an essential part of the lives of those who live on its banks" (SAfAIDS 2011, 3). As such, "the model acknowledges the need for communities to respect, hold close, and strengthen the aspects that protect families and individuals, and which enrich lives"(Price as cited in: SAfAIDS 2011, 2) The primary image of this campaign is of a man carrying a woman across the river, described by a respondent as depicting "men as protectors."²⁸⁵

This process is thought to be successful because, as solutions and linkages originate from communities there is a higher level of community ownership and of community-appropriate solutions. The process, or the 'how' of the intervention, in terms of the structure of the intervention was what respondents focused on most strongly when describing how this intervention was different, and why it held promise. Correspondingly, process was what was

²⁸³ Author's interview, Employee 2, Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), 12 August 2010, Pretoria, Gauteng, South Africa.

²⁸⁴ Author's interview, Employee 1, Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), 12 August 2010, Pretoria, Gauteng, South Africa.

²⁸⁵ Author's interview, Employee 3, Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), 26 August 2010, Pretoria, Gauteng, South Africa.

understood as being linked to impact. According to the SAfAIDS website over 500 cases of gender-based violence “have been referred to legal authorities” which “giv[es] credit to the impact the community sensitisation meetings and dialogues have on the communities” (SAfAIDS website – Changing the River’s Flow, 2012). There has also been the establishment of an anti-sexual cleansing group, composed of former sexual cleansers, and the establishment of community-based committees to “sensitise their community with regard to the inter-linkages between culture, gender-based violence, women’s rights and HIV (SAfAIDS website – Programme Stories, 2012). This campaign, while overtly making rights references in its materials, places dominant emphasis on culture as the gateway to change, and as the most approachable and appropriate frame from which to conduct grassroots-based advocacy.

5.2.3.1.2 Policy Dialogues: Legal Change in Zimbabwe and Malawi

Policy dialogues were heavily emphasised as a key component of advocacy, with respondents highlighting two recent policy dialogues,²⁸⁶ one in Zimbabwe and one in Malawi. Both were aimed at the modification of laws and focusing on rights. In the two instances SAfAIDS worked with national networks of people living with HIV/AIDS: Zimbabwe National Network for Positive People (ZNNP+) and Malawi National of People Living with HIV/AIDS (MANET+). The dialogues aimed to connect these national networks to parliamentarians and were kicked off by a regional training after which participants went back to their home countries to identify key areas of concern and key actors. As such while, holding common threads each national policy dialogue has a slightly different emphasis.

²⁸⁶The initial Zimbabwe policy dialogue occurred on 7 August 2009, initial Malawi policy dialogue occurred on 8 September 2009.

The Zimbabwe policy dialogue focused on the development of the country's new constitution, with the aim of "engaging parliamentarians and government on how the right to health can be included in the constitution's bill of rights."²⁸⁷ When conducting community-level dialogues, facilitators asked "Do you think it's strategic for us to advocate for a right? ...What do you want to be included in the new constitution?"²⁸⁸ The groups decided that constitutional recognition of the right to health was key, in concert with SAfAIDS drafting a position paper that was submitted to the committee responsible for drafting the new constitution, and speaking directly to the issue at local and national consultation meetings. Network members were cited in the Zimbabwean press calling for "recogn[ition of] the right to health as a basic right that should be guaranteed in the new constitution" further detailing that this recognition "should identify the right to health as encompassing the provision of adequate and quality health care, diagnostic testing, access to treatment, free anti-retroviral drugs (ARVs) to those who need them and transparency in the administration of health resources" (Chief Reporter 2005). At the time of interviews, the Constitution had not yet been finalised (Voa News 2012), with SAfAIDS respondents noting "we hope the network will be successful in advocating for the right to health to be included in the bill of rights."²⁸⁹ In SAfAIDS records of the outcomes of policy dialogues, this dialogue was referenced as resulting in one documentary, and one position paper (SAfAIDS website – Policy Dialogues, 2012).

²⁸⁷ Author's interview, Employee 1, Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), 12 August 2010, Pretoria, Gauteng, South Africa.

²⁸⁸ Author's interview, Employee 1, Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), 12 August 2010, Pretoria, Gauteng, South Africa.

²⁸⁹ Author's interview, Employee 1, Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), 12 August 2010, Pretoria, Gauteng, South Africa.

In Malawi, the policy dialogue took place in the context of the drafting of an HIV/AIDS bill. This bill, and others like it was influenced by the N'djamena model law, a piece of legislation which includes provisions widely seen by rights advocates as discriminatory and punitive to those living with the virus (2007). In this case the dialogues resulted in advocacy around minimising discriminatory and criminalising language. The position paper explicitly employs a rights frame and illustrates a number of influences, specifically referencing the N'djamena model law, as well as the SADC model alternative law which emphasises rights. In its opening statement, the position implicitly describes these two positions pulling in opposing directions:

As Malawi enacts an HIV law, it has the choice between the various approaches, and can decide to further progress in public health and human rights or punish HIV transmission and mandate testing and disclosure, further stigmatising HIV. This position paper highlights the various draft provisions in light of international human rights norms and points out how the Malawi HIV Bill can be altered to one that furthers progress towards stopping the spread of HIV (A Coalition of NGOs, Donors, Multilateral Organisations, and Faith-based Organisations 2010).

Praising proposed non-discrimination provisions with respect to employment (Article 29), the position paper raises concerns about compulsory testing, forced disclosure, and pays particular attention to criminalisation (Articles 44 and 45). Mirroring arguments raised by ARASA in their own campaign on this topic, the paper notes that criminalisation is known to have a disproportionate and negative impact on women and, in doing so, “may contravene the gender equity provisions of the Malawi Constitution as well as international conventions such as Convention on the Elimination of Discrimination Against Women” (A Coalition of NGOs, Donors, Multilateral Organisations, and Faith-based Organisations 2010).⁷ SAfAIDS norm of engagement is also apparent in this document, where, in reference to harmful traditional practices it is noted that, “evidence from other settings shows that a period of consultation with community and traditional leaders to explore safe alternative practices may lead to better

outcomes and prevent these harmful practices from being continued clandestinely”(A Coalition of NGOs, Donors, Multilateral Organisations, and Faith-based Organisations 2010). The bill concludes “urg[ing] the state to consider excising several problematic provisions in the draft Bill and input alternative language, transforming the draft Bill into one that protects human rights and helps further prevent the spread of HIV in Malawi” (A Coalition of NGOs, Donors, Multilateral Organisations, and Faith-based Organisations 2010).

Contrary to popular practice, the network and its allies succeeded in convincing the President to re-examine the bill at a relatively late stage in the process in order to re-evaluate the language within it. Respondents noted that “the fact that this reversal has taken place is a milestone on its own” as this step is quite unusual.²⁹⁰ The bill has not been tabled in parliament, and SAfAIDS notes that the outcomes of this advocacy initiative are that the position of people living with HIV has been “re-affirm[ed],” the debate on the bill was reopened, and that there is “consideration to review the draft HIV legislation currently under examination by the Cabinet Committee on HIV and AIDS in the Office of the President and Cabinet” (SAfAIDS website – Policy Dialogues, 2012). Despite the fact that the bill has not yet passed, SAfAIDS respondents felt that when it was considered in parliament it would be in “much, much better form”²⁹¹ noting that “our advocacy efforts led to them contributing to the language for the AIDS/HIV bill in Malawi.”²⁹² In these two cases rights were quite prominent in the substance and objectives of both initiatives.

²⁹⁰ Author’s interview, Employee 1, Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), 12 August 2010, Pretoria, Gauteng, South Africa.

²⁹¹ Author’s interview, Employee 1, Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), 12 August 2010, Pretoria, Gauteng, South Africa.

²⁹² Author’s interview, Employee 2, Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), 12 August 2010, Pretoria, Gauteng, South Africa.

Even so, SFAIDS respondents placed a primary emphasis on the process of collaborative engagement and dialogue.

5.2.4 Conclusions: SFAIDS

SFAIDS emphasises the form of its advocacy over the frame, highlighting the importance of dialogue as a catalyst for change. The group predominantly employs a development approach, but also makes strong links to other frames including rights and gender in specific campaigns. Unlike some other groups studied, SFAIDS prefers to conduct advocacy ‘from behind’ seeing its role building the capacity of community groups, parliamentarians and others to carry out advocacy publically.

Intra-organisational factors including the organisational set-up and structure, which emphasises material production and consultation have strongly influenced the group’s approach. External factors, including the cultural diversity faced by a regional organisation working in multiple countries appear to have contributed to the group’s focus on a dialogue-oriented process in all forms of advocacy. Perceptions of impact were also overwhelming linked to the process of advocacy, rather than the method, although one respondent highlighted the group’s ability to distance itself from emotion and present a more objective policy-oriented approach.

5.3 The AIDS Support Organisation (TASO)

*“A world without AIDS”*²⁹³

²⁹³Noerine Kaleeba as cited in TASO website - Christopher Kaleeba Day 2010: TASO to recommit to strengthening values and vision.

One of the earliest HIV organisations, TASO initially existed in the dire context of a pandemic without the existence of anti-retroviral medication. Founded by personnel with backgrounds in the health sciences who had been directly impacted by the virus, concepts of care and family were initially dominant within the organisation. Over time, the group developed international connections and became recognised in part for its emphasis on giving people living with HIV/AIDS a prominent role. The large national organisation contains diverse opinions with respect to the prominence of rights in their work, with some employees seeing the frame as dominant, and others viewing it as more peripheral. This group demonstrates the weakest connection to rights of the organisations in the rights mixed category, but still a more substantive connection than those in the subsequent rights limited group. Employees who had been with the organisation longer, particularly those who were founding members, were more likely to cite rights as important as were those involved more directly in advocacy as opposed to service provision.

As a case TASO illustrates fit with a very limited number of hypotheses seeking to explain rights choosing. Intra-organisational factors including leadership, founding staff and personal experiences play an important role in shaping the perspective and operations of the organisation. However, the rights orientation held by some of the founding staff do not appear to transfer to others in the organisation. Structurally, TASO is a large decentralised membership organisation with multiple offices, a setup that facilitates diverse viewpoints. Externally, the group is situated in a context where rights is not a dominant domestic discourse. The group is, however, well connected internationally including to rights dominant groups and to some international donor who favour a rights approach. In contrast to rights dominant groups, however, the Ugandan government is also a significant funding partner. As with NACWOLA, organisational identity

and niche are strongly tied to constituency above all else. As with SAfAIDS TASO respondents primarily associate impact with advocacy techniques rather than frame.

5.3.1 Frame

“Living Positively with HIV/AIDS”²⁹⁴

“Living positively” is the concept for which TASO is best known, emphasising life in the face of very high death tolls early in the pandemic. While not dominant, rights appear in several locations in key documents reflecting TASO’s purpose and mandate. The mission’s dominant focus is on positive living, including specific sections on personal, family, community, national and international level goals. Rights are referenced once at the individual level (“facilitate the balance between rights and responsibilities”), stigma and discrimination is referenced once at the community level, while positive living, quality of life and care are each noted twice, and mobilisation appears four times.²⁹⁵ TASO’s organisational values place a slightly higher emphasis on rights, listing “human dignity, obligation to people infected and affected by HIV/AIDS, equal rights, shared responsibilities, equal opportunities, family spirit, and, integrity” (Ssebbanja, Kalinaki and Williams 2007, 23). Among posters observed in TASO Mulago/headquarters,²⁹⁶ two of four TASO- produced posters contained rights references²⁹⁷ and five of the fifteen materials that were produced by other organisations, with no dominant counter frame evident in materials displayed.

²⁹⁴TASO website – About.

²⁹⁵TASO Poster titled “TASO Mission” observed at TASO Mulago in March 2010.

²⁹⁶All posters observed in March 2010. Posters observed in public areas of the office (ie not individual offices). A complete listing of posters observed is provided in Appendix B. TASO Mulago and TASO headquarters share a building.

²⁹⁷Three of these posters were produced exclusively by TASO, one jointly with other organisations. The two posters referring to rights were a poster listing TASO values and one listing TASO’s mission statement.

Interview respondents reflected similar themes, with rights mentioned by five of seven respondents who directly addressed the organisation's frame. The role of rights varied in prominence among respondents. Three TASO respondents noted rights as the dominant approach, with one listing rights in combination with gender. Poverty was highlighted by two respondents, and one saw development as the overarching frame followed by gender and human rights. One person commented that TASO's activities could not be limited to one frame as, "preventing HIV infection, fostering hope and improving the quality of life for a persons' families and communities affected by HIV infection and disease – that is not isolated to any one perspective for it" elaborating that a number of different approaches were used depending on the campaign, including gender and rights among others.²⁹⁸ Two respondents who had been with the organisation since its outset and contributed to its founding made regular, un-probed reference to rights throughout the interview, as did one more recent employee with an explicitly advocacy-oriented position. Most employees who had joined TASO more recently were more likely to primarily emphasise care and support in their responses.

5.3.2 Intra-Organisational Factors Affecting Frame Selection

*"We had all experienced or observed the rejection and discrimination faced by people living with HIV and their families."*²⁹⁹

TASO was founded in 1987 by physiotherapist Noerine Kaleeba and 15 colleagues, 12 of whom were living with the virus at the time and died within the organisation's first year. Initially a small support group based at Kampala's Mulago hospital, the group was strongly personally affected by the pandemic, and this proximity to personal experiences of devastation had a strong impact on the organisation's identity and perspective. The organisation grew to meet the need

²⁹⁸ Author interview, Employee, TASO, 1 March 18 2010.

²⁹⁹ Ssebhanja, Kalinaki and Williams 2007, 6.

and now has 11 service centres and four regional offices throughout Uganda, with headquarters in Kampala employing 90 people, with a total staff of more than 1,000 (Ssebbanja, Kalinaki and Williams 2007, vi). Interviews were carried out with a total of ten employees at TASO Mulago and headquarters.³⁰⁰

Referred to as “one of the largest indigenous Non Government Organisation[s] providing HIV/AIDS services in Uganda and Africa” (TASO Website - About, 2012) TASO is one of the country and continent’s earliest support organisations. The group provides direct care through an antiretroviral therapy programme, conducts counsellor training, provides social support, supports community HIV programs and “carr[ies] out HIV education and advocacy, both nationally and internationally, on behalf of people living with or affected by HIV” (TASO 2011, 1-2). TASO has “registered over 200,000 clients since inception in 1987 and has cumulatively enrolled over 40,000 clients on Antiretroviral Therapy (ART) since 2004” also supporting 5,000 children (TASO Website-About, 2012). The group continues to have a strong emphasis on support and hosts Positive Men’s Unions (POMU) and Mama’s Clubs (support groups for mothers) at several of its locations. The group also notes that it has “contributed to founding and nurturing” these two groups as well as Traditional and Modern Health Practitioner Together Against AIDS (THETA), the Ugandan National Association of AIDS Service Organisations (UNASO), and the National Community of Women Living with HIV/AIDS (NACWOLA) (TASO 2008, 2). The group is also known for its community mobilisation and educational outreach, including a popular drama group.

³⁰⁰The district office and headquarters share a building, interviews were carried out with employees in both offices, as well as with one individual normally based in the Entebbe office, and one former employee.

5.3.2.1 Organisational History and Personnel

TASO's beginnings were, and remain inextricably linked to personal experiences of HIV. Experiences of stigma and isolation had a particularly strong influence on TASO's perspective which is reflected in the group's emphasis on 'positive living' and 'family spirit.' While not dominant, some respondents argue that over time rights gained a more significant profile, as treatment became available and those living with the virus came to be seen as active participants in their care.

Christopher Kaleeba, founder Noerine Kaleeba's husband, was diagnosed with AIDS in 1986 while pursuing a PhD in the United Kingdom. At the time the disease was new and feared, and few treatment options existed, however, the couple was initially received with compassion. Noerine Kaleeba described the experience, stating:

The nurses were very afraid for me. I was impressed from the start by the attitude of the staff towards us. It was not long before I established that we were the only black couple on the ward, and their first heterosexual patients living with AIDS. Despite having two ingredients for stigma, we were treated with such care and compassion that it left an everlasting mark on me. It was then that I resolved that if God would allow me time and life I would like to return this kind of care to patients (Kaleeba and Ray 2002, 16).

On return to Uganda, however, the couple's experience with healthcare stood in "stark contrast" (Ssebbanja, Kalinaki and Williams 2007, 5) to the U.K. The support they had received there was "sorely missed" and Kaleeba noticed that others in the hospital dealing with HIV/AIDS also lacked support (Ssebbanja, Kalinaki and Williams 2007, 2). Although as a physiotherapist

working with people with disabilities Noerine considered herself “already an activist for the stigmatised,” she was still unprepared for the HIV-related stigma she encountered.³⁰¹

Kaleeba reported an early meeting on HIV in Uganda where a government official in the Ministry of Health proclaimed that the obvious solution to the virus was to place all of those with it on islands in Lake Victoria and “forget them.”³⁰² In this context of intense stigmatisation, Noerine and 15 colleagues, gradually came together to provide support to people living with HIV/AIDS, with a focus on ‘positive living’ and involvement of people living with the virus (Kaleeba as cited in: Ssebbanja, Kalinaki and Williams 2007, vi). One founding member noted, “[w]e were just a small group of concerned individuals doing our best to support one another and others in need of help because of the impact of AIDS on our lives” (Ssebbanja, Kalinaki and Williams 2007, 6). In a publication on the group’s history two founders described the organisation’s initial vision:

We came together to seek refuge from the stigma and discrimination we were experiencing, and to find strength in sharing our experiences. We discussed how to care for those living with AIDS. We shared food and offered what little surplus we had to those who had nothing. We visited one another, in our homes or in hospital, to offer prayer and comfort (Ssebbanja, Kalinaki and Williams 2007, 1).

What we did from the start, almost instinctively, without really having any scientific proof of its validity, was to focus our efforts on the person who is infected or affected by HIV. I celebrate the fact that we focused on the quality of life, and on restoring dignity, both in life and in death” (Kaleeba as cited in: Ssebbanja, Kalinaki and Williams 2007, vi).

³⁰¹ Author’s interview, Noerine Kaleeba, The AIDS Support Organisation (TASO), 12 March 2010, Kampala, Uganda.

³⁰² Author’s interview, Noerine Kaleeba, The AIDS Support Organisation (TASO), 12 March 2010, Kampala, Uganda.

Over time the group grew from a small entirely voluntary organisation composed largely of health care professionals, to a one-room group with one paid employee. TASO was registered as an NGO in 1987 and by 1989 the group had codified its mission, values and work ethos which emphasised care in all forms, changing attitudes, positive living, rights, obligations and responsibilities and family spirit (Ssebbanja, Kalinaki and Williams 2007, 23). The scope of TASO's activities changed dramatically in 2003 when ARVs became available in Uganda. As one of the founders, Peter Ssebbanja noted "[t]wenty years later TASO still promoted 'positive living,' but now works to keep people living with HIV alive and healthy, rather than resigning themselves to a premature death, whether 'dignified' or not" (Ssebbanja, Kalinaki and Williams 2007, 3).

As the organisation grew over time, founding members noted some organisational shifts in relation to rights. Founder Noerine Kaleeba noted that in TASO's early days they "focus[ed] more on service delivery" and "provid[ing] people with service as opposed to empower[ing] people to speak and claim their rights."³⁰³ She commented that there is now "the beginning of the realisation that you cannot provide services almost passively to people without getting them involved without them taking charge of their lives."³⁰⁴ Another founding member felt that TASO's mandate and activities had been linked to rights from the beginning commenting that advocating for and providing care and support was "in a way we [were]... talking about activism

³⁰³ Author's interview, Noerine Kaleeba, The AIDS Support Organisation (TASO), 12 March 2010, Kampala, Uganda.

³⁰⁴ Author's interview, Noerine Kaleeba, The AIDS Support Organisation (TASO), 12 March 2010, Kampala, Uganda.

first. In a way we were really concerned about the rights of these people,” however he noted that in the past rights had not been mentioned as explicitly as they are currently.³⁰⁵

5.3.2.2 Organisational Values

TASO’s organisational values originated from the particular challenges and realities experienced by its founders and members and were codified in the late 1980s and early 1990s. Reacting to stigma and rejection, these values emphasise dignity, unity, and equal access to treatment, each positive value a response to a negative experience. While rights is a theme that emerges at various points among these values and in respondents discussion of them, it is one of several themes embedded in a larger experiential story of coming together in a context of crisis.

‘Positive living’ became the group’s mantra early. In a context of limited options and a high level of stigma, the focus was on leading a good life, “mak[ing] the best of whatever time they had left” and undertaking the necessary preparations to “die with dignity” (Ssebbanja, Kalinaki and Williams 2007, 1). Founding member Peter Ssebbanja noted that the value pronouncing the obligation of care emerged from a situation where people with HIV were being ignored by medical personnel. Similarly, the value of equal rights, responsibilities and opportunities came from witnessed inequities in treatment. He explained:

we were seeing a patient of malaria receiving better care than the patient that has been diagnosed with AIDS [and who also has malaria]. Why shouldn’t they have equal opportunities? Why shouldn’t they have equal rights? If there is medicine for malaria for this one, and this one also has malaria they should receive the same medicine, the same dose, the same attention and so on. But people tended to think that if somebody has AIDS and malaria, we should [treat the one who only has malaria]. After all that one [with

³⁰⁵ Author’s interview, Peter K. Ssebbanja, The AIDS Support Organisation (TASO), 18 March 2010, Kampala, Uganda.

malaria and AIDS] is going to die. That's what they thought. But this one: only malaria! No HIV! We should treat this one. That's how that one came in: equal opportunities, equal rights. Even these guys with AIDS were denied some medicines at that time, not today. Today things have changed.³⁰⁶

Other values were also prompted by witnessed and experienced absences, and an attempt to compensate for the stigma and alienation that was dominant in society, family and medical environments at that time, and in a context when anti-retrovirals were not yet available. Human dignity, for example emerged because, "at that time there was not dignity for people living with HIV, family members decided to abandon them, medical staff was not bothering about them" with one respondent noting, "that was when we said we must focus on the rights of people living with HIV."³⁰⁷ Integrity emerged as a value to emphasise the need for health care workers to do their jobs honestly, sincerely and to the best of their abilities.³⁰⁸

The TASO "family spirit" also became a key organisational value. In a context of rejection by blood relatives, TASO "regarded our clients as fellow members of the TASO family, and as such they deserved maximum compassion and empathy" (Ssebbanja, Kalinaki and Williams 2007, 9). Being warm, welcoming and positive were key cornerstones of the organisation. As Ssebbanja commented:

[w]hen it comes to the family spirit because we realised at that time the families were being torn apart we said I think TASO is another family which brings welfare and we should be treating each other as family members. We should promote the family spirit in all the families and communities.³⁰⁹

³⁰⁶ Author's interview, Peter K. Ssebbanja, The AIDS Support Organisation (TASO), 18 March 2010, Kampala, Uganda.

³⁰⁷ Author's interview, Peter K. Ssebbanja, The AIDS Support Organisation (TASO), 18 March 2010, Kampala, Uganda.

³⁰⁸ Author's interview, Peter K. Ssebbanja, The AIDS Support Organisation (TASO), 18 March 2010, Kampala, Uganda.

³⁰⁹ Author's interview, Peter K. Ssebbanja, The AIDS Support Organisation (TASO), 18 March 2010, Kampala, Uganda.

While all of these values are retained currently, several members noted changes over time. As remarked above differential treatment is less of a problem, and ARVs are now available dramatically changing the landscape of life with HIV in Uganda.

The role of rights, a concept reflected among both the organisational values and respondents' reflections on them, were also perceived by some to have shifted over time. Respondents commented that rights, despite their reference in TASO's values, had not initially been prominent but had become so. Ssebbanja, a founding member, argued that "even in the 80s we talked about human rights" but also noted that rights while "not new" were "more vigorous" at the current time commenting that in the earlier days "we were talking so much about professionalism. You are a doctor. You should treat this patient. But behind it has got the human rights, okay?"³¹⁰ An employee responsible for representing TASO in advocacy and policy fora at national, regional and international levels commented that in the current advocacy context, "most times it's actually a rights-based approach, we have tried to use human rights as cross-cutting, across every type of advocacy that we do" highlighting the right to treatment, gender-based rights, "the right to a stigma-free environment" and children's rights.³¹¹ Among employees involved more directly in service provision, rights were significantly less prominent with care and support receiving more attention.

Among current organisational documents, the reflection of rights as a core value is apparent but not dominant. TASO's listed achievements over its history, for example, include a record of

³¹⁰ Author's interview, Peter K. Ssebbanja, The AIDS Support Organisation (TASO), 18 March 2010, Kampala, Uganda.

³¹¹ Author's interview, Dr. Lydia Mungherera, The AIDS Support Organisation (TASO), 12 March 2010, Kampala, Uganda.

service provision, stigma reduction, training, mobilisation, “br[inging] to the fore issues highlighting and advocating for the rights of people living with HIV/AIDS” and being “at the forefront of advocating for equal rights, shared responsibilities and equal opportunities” (The AIDS Support Organisation website – Achievements, 2012). Among the nine goals for the 2008-2012 Strategic Plan one highlights rights in the context of gender, stating the group aims to “contribut[e] to enhancement of gender mainstreaming in HIV prevention, care and support services through a rights based approach” while other goals highlight service provision, advocacy and human resources (TASO 2008, 117, 69-137). The comprehensive Strategic Plan contains only occasional reference to rights, with explicit mention occurring approximately once every 12 pages (TASO 2008). These include references to the rights of people living with HIV/AIDS, of vulnerable groups, of rights violations in the context of warfare in northern Uganda, partnerships, human rights training and child rights. There are also two references to the rights section of the group’s vision – including its invocation as the impetus for the establishment of TASO Centres in post-conflict Northern Uganda. Among the various lists of goals and objectives rights do not feature prominently and are dwarfed by operational and programmatic goals, access, and gender mainstreaming. Six activities (of more than 400) include a reference to rights (TASO 2008).

5.3.3 Extra-Organisational Factors Affecting Frame Selection

*“People living with HIV and AIDS were seen as dying. We adopted the slogan “Living positively with AIDS” in direct defiance of that perception.”*³¹²

5.3.3.1 Domestic Factors

Domestic factors were critically influential shaping both the messaging and method of TASO advocacy. Respondents mentioned the consequences of early HIV prevention messaging, as well as cultural factors at the community level as having an impact on the form and content of advocacy. Confronted with fear-based messaging and stigma, the group shaped their frames in response, and, as Kaleeba notes above “in direct defiance” of the context in which they found themselves.

Respondents who had been associated with TASO since the beginning argued that early HIV prevention strategies had a strong influence on the way in which TASO chose to formulate its identity and advocacy. In the absence of treatment, early HIV strategies in Uganda were focused almost entirely on prevention and, as was the case elsewhere in the world, emphasised fear. Rapid traditional drumming indicating warning was played half-hourly on television and radio, followed with the simple but ominous message “AIDS kills.” While possibly an effective tactic of dissuasion, the message that “[y]ou can catch it and you are as good as dead” (Kaleeba and Ray 2002, 32) offered “no recognition that we are talking to a population that ha[s] both people who are HIV negative and those who already ha[ve] HIV.”³¹³ Another early slogan “love carefully” was also cited problematic for those already living with the virus, as it “stigmatised people with AIDS. It said, look these are the people who have loved carelessly” (Kaleeba and

³¹²Kaleeba and Ray 2002, 32.

³¹³Author’s interview, Noerine Kaleeba, The AIDS Support Organisation (TASO), 12 March 2010, Kampala, Uganda.

Ray 2002, 32). Relying on messages of fear and death there were “hardly any messages of living with HIV and hope in those days,”³¹⁴ instead, “[w]hat was implied was that people who were already infected should die and get it over with” (Kaleeba and Ray 2002, 39). In contrast with these messages, TASO emphasised positivity and focussed initially very precisely on those living with the virus, in later years expanding to include families more explicitly.

In contrast with the invisibility of people with HIV, or their profile limited to potential sources of infection, TASO also advocated for the inclusion of people living with HIV as part of the solution. One respondent noted:

as the activism began and TASO began to really bring the visibility of people with HIV the realisation began to hit that you cannot prevent HIV transmission if you do not care for those who have HIV if you don’t get them into a situation where they feel that it is in their interest that not more people get infected.³¹⁵

A critical component of this visibility hinged on a public presence. Noerine Kaleeba, who for many years was uncertain of her own status, and chose to ‘live positively’³¹⁶ commented that “[f]or almost two years, I was the only person in Uganda who spoke on TV and radio about living with HIV” (Kaleeba and Ray 2002). A major change cited by Kaleeba and others was when well-known Ugandan singer Philly Lutaaya openly stated his HIV status, Kaleeba noted, “[h]is going public was the watershed, and since then hundreds have gone public, though rarely from the elite such as politicians or top business people” (Kaleeba and Ray 2002, 39-40).

³¹⁴ Author’s interview, Noerine Kaleeba, The AIDS Support Organisation (TASO), 12 March 2010, Kampala, Uganda.

³¹⁵ Author’s interview, Noerine Kaleeba, The AIDS Support Organisation (TASO), 12 March 2010, Kampala, Uganda.

³¹⁶ She tested negative in England but was told she would have to re-test (there can be an incubation period where those recently infected test negative) and did not for many years assuming herself to be positive.

Along with this public shift of visibility, there was also a shift among medical professionals noted by a few respondents from viewing their patients of passive recipients of care to active participants in their health care. This transition from “my patient – to a person who has rights and who has hopes and who has expectations”³¹⁷ was not an easy one. One respondent also noted that “cultural submissiveness interferes with empowerment” and that “there has been an evolution but the evolution has been very slow.”³¹⁸

5.3.3.2 International Factors

TASO, although a clearly indigenous Uganda organisation, has, from its inception, been exposed to some level of international exposure and influence. These international influences have played a key role in linking TASO’s experience to international perspectives on the pandemic, with several respondents commenting on international exposure to rights language. When Christopher Kaleeba was diagnosed in the United Kingdom, his and his wife Noerine’s first experience of HIV treatment and coping strategies were overseas. Noerine Kaleeba recounted this experience:

for me, I think the energy, the power and the strength to actually come out and fight the stigma associated with HIV was ignited by a very early experience that I had interacting with gay men in the northern hemisphere. When I talked about advocacy and the activism that has arisen around HIV that has brought us closer and closer to dignity and access I always have a *great* [spoken emphasis] respect for the response of gay men at first in the US and in the UK because when my husband was diagnosed and was in hospital at Castle Hill the first notion, the seed about fighting and responding and actually standing up to be counted was actually shown to me by two gay men who were part of the buddy system who came to the hospital.³¹⁹

³¹⁷ Author’s interview, Noerine Kaleeba, The AIDS Support Organisation (TASO), 12 March 2010, Kampala, Uganda.

³¹⁸ Author’s interview, Noerine Kaleeba, The AIDS Support Organisation (TASO), 12 March 2010, Kampala, Uganda.

³¹⁹ Author’s interview, Noerine Kaleeba, The AIDS Support Organisation (TASO), 12 March 2010, Kampala, Uganda.

Noerine Kaleeba linked rights and HIV, both globally and in her own experience to specific actors. These included gay men, who she credits with “ignit[ing] the thinking” of “linking health and human rights” both generally and specifically in reference to HIV, and UNAIDS founder Jonathan Mann who she listed as “one of [her] inspirational human beings” and with whom she visited and consulted with early on about her husband’s condition, a conversation Mann, later a health and human rights scholar, would remember as pivotal.³²⁰

At the headquarters level most respondents had had first-hand international experience primarily in the form of travel to attend conferences or trainings, though those engaged in policy were far more likely to than those involved in service provision or service management. One respondent was present at the signing of the President’s Emergency Fund for AIDS Relief in Africa (PEPFAR) agreement by George W. Bush and travelled with Bono and Ashley Judd on a public education tour across the United States. Respondents reported having attended international conferences as early as 1989 (Montreal) and listed having been to events in Canada, Kenya, the United States, the United Kingdom, Japan, South African and Germany, as well as having had visitors from organisations on various parts of the African continent including Treatment Action Campaign (TAC) founder Zackie Achmat. Respondents also referenced visits from other African organisations for whom TASO sometimes provided training.

In addition to personal international linkages, TASO has also had international employees and volunteers, including a three-year Voluntary Service Overseas (VSO) volunteer early on who conducted basic counselling training. TASO continues to regularly receive volunteers, participate

³²⁰ Author’s interview, Noerine Kaleeba, The AIDS Support Organisation (TASO), 12 March 2010, Kampala, Uganda.

in internship programs and collaborate with international researchers. No respondents, however, linked these international personnel with a rights-based approach in either a positive or negative way.

One respondent made specific linkages between rights and international connections commenting that the International Council of AIDS Service Organisations (ICASO) had provided advocacy workshops which “took us through human rights” and noting “[s]o we went to these conferences. We met many of these activists from Canada, from the UK, from South Africa, from where we got those activists who were giving us more to learn about these human rights violations and so on.”³²¹ The group is part of several regional and international networks including African Civil Society Organisations, the International Treatment Preparedness Coalition, the East Africa Treatment Access Movement and the East African Network of Women with HIV/AIDS. While the majority of respondents had travelled overseas and had direct experience of international interaction, respondents were drawn primarily from the organisational headquarters. Those engaged primarily in service delivery and centre management were less likely to have travelled overseas. Although not a one to one correlation those with direct international experience were more likely to refer to rights than those who had not, who tended to emphasise services almost exclusively.

5.3.3.3 Donors

TASO began as an entirely voluntary organisation with no external funding. Gradually donations began coming in in-kind, as well as space and personnel from the Ministry of Health. Action

³²¹ Author’s interview, Peter K. Ssebhanja, The AIDS Support Organisation (TASO), 18 March 2010, Kampala, Uganda.

Aid was an important early donor providing fuel and a vehicle which enabled home visits, USAID became a donor in 1989/90 and around that time key personnel began resigning from their jobs in order to take on full time paid positions within TASO. By 1991-92 the group had begun writing formal funding proposals. The group has received funding from a diverse array of sources including the Government of Uganda,³²² European,³²³ North American³²⁴ and Japanese³²⁵ development assistance, private foundations,³²⁶ companies,³²⁷ UN Sources,³²⁸ and targeted funding agencies such as PEPFAR and the Global Fund. While these are many of the same donors as with other organisations studied, TASO has a comparatively greater government funding and greater US involvement, both groups that are comparatively less likely to emphasise a rights approach. Several respondents noted that rights had become a more dominant approach at local and global levels lately, with one respondent noting “[t]hose who do funding it is with the human rights”³²⁹ While TASO may have been influenced in the circa 2003 period when there was a movement away from rights, there are no obvious indicators that donors actively dissuaded or persuaded work on rights, though in comparison with other groups TASO has had a greater proportion of donors without an overt rights focus.

5.3.4 Impact

Similar to SAfAIDS, methods of advocacy were highlighted as having critical connections to impact, more so than frame. Key features of successful advocacy noted by respondents included: the importance of tailoring messages to the audience, the benefits of collaboration and the critical

³²²Uganda Ministry of Health, Uganda AIDS Commission

³²³DFID, DANIDA, Irish Aid, European Union

³²⁴USAID, CIDA, CDC

³²⁵JICA

³²⁶Elton John Foundation, Rockefeller Foundation

³²⁷Celstel, Johnson and Johnson, Pfizer

³²⁸UNICEF

³²⁹Author’s interview, Joshua Wamboga, The AIDS Support Organisation (TASO), 16 March 2010, Kampala, Uganda.

task of capacitating people living with HIV to advocate on their own behalf. Due to TASO's emphasis on indirect methods of advocacy, this section examines perceptions about impact, but, in contrast with the other groups examined, does not trace individual campaigns.

Respondents highlighted the importance of the 'fit' between the message and the recipient. Cultural factors, in particular, were cited as important influence on choice of frame, in some cases posing challenges to the use of rights, particularly with reference to gender. One respondent noted, in the "traditional man- woman relationship where there is male dominance men may not see why women have the right to do so many things."³³⁰ Because of challenges like this, it was noted that while a rights approach may dominate in a policy or government context, in communities the choice was often made to instead focus on a "moralistic approach" which was seen as more accessible, arguing, for example, that "it's a moral issue to stop beating up your wife, it's a moral issue to get treatment, it's moral issue to let the person live in a stigma-free environment."³³¹

Confrontational approaches were singled out as counterproductive and unlikely to result in the desired outcome, with respondents instead emphasising the importance of collaboration. Two respondents made a point of distinguishing TASO's advocacy more confrontational forms that they had witnessed overseas, which were sometimes described with obvious shock. Respondents made comments such as "[y]ou know that activism where people throw their arms up? It wasn't

³³⁰ Author's interview, Dr. Lydia Mungherera, The AIDS Support Organisation (TASO), 12 March 2010, Kampala, Uganda.

³³¹ Author's interview, Dr. Lydia Mungherera, The AIDS Support Organisation (TASO), 12 March 2010, Kampala, Uganda.

here. Up to now we have not come to that level of where people become like Act Up.”³³²

Another respondent elaborated:

[I]n TASO the outlook that we’ve taken to advocacy, the approach we’ve taken, is not confrontational. It’s not activism. It’s not getting out to the streets and saying “I want my ARVs. We want access. We want Human Rights” But it’s been rather a peaceful advocacy where we join with other partners across the country.³³³

Collaboration was highlighted as a critical component of effective advocacy.

One respondent, in line with comments noted earlier about avoiding a confrontational approach noted that an approach which entailed making demands or shaming government would be inappropriate and counter productive given the group’s long-time collaboration with government and partnership perspective.

Just like you see here, most of TASO centres are within government hospitals. The government gives us land and then we put up buildings. We are contributing to the process, to the work of the Minister of Health. So to stand up and start saying, “Look this is what...” it hasn’t worked. We thought it wasn’t very appropriate in our setting here. Why has TASO taken up the idea of collaborating with other organisations? The founding of TASO it goes back to the mission and the objectives of the organisation. The founding of TASO was really a spontaneous approach to respond to the need at the time. It was not one man’s issue.³³⁴

Another respondent, concurring with the above sentiment, argued, it was best to capacitate TASO members to conduct advocacy on their own behalf by providing them with good care and allowing them to see the contrast between standards in TASO and some government facilities. This respondent argued that part of TASO’s role was not to advocate directly, but to enable TASO members to advocate for themselves, in part by treating them as they should be treated

³³² Author’s interview, Peter K. Ssebhanja, The AIDS Support Organisation (TASO), 18 March 2010, Kampala, Uganda.

³³³ Author’s interview, Employee, The AIDS Support Organisation (TASO), 18 March 2010, Kampala, Uganda.

³³⁴ Author’s interview, Employee, The AIDS Support Organisation (TASO), 18 March 2010, Kampala, Uganda.

and providing them with good quality services, so that they come to expect these and question when they do not receive the same respect in other locales.

5.3.5 Conclusions

TASO is a large and diverse organisation with differing viewpoints in relation to dominant organisational frames, which vary both over time (the time frame of the organisation and length of time people have spent with the organisation) and by position (policy and advocacy-oriented positions, versus service provision). Those with a personal experience of isolation and a longer connection to the group were more likely to cite human rights and were also more likely to have had some international exposure. Those involved more directly in service provision were more likely to see care as a primary approach, with an emphasis on partnership, with poverty, development and gender seen as critical frames.

Internal factors including personal experiences of founders and current members, played a key role in shaping the organisation's niche, identity and perspective emphasising unity, equality and support in the face of stigma and rejection. These personal experiences were reinforced by early HIV interventions which emphasised fear and were felt to further victimise those living with the virus. International interactions appear to have been important in bringing ideas of rights to at least some key personnel within TASO, however, these ideas do not appear to have penetrated the overall organisational approach, instead existing as themes or topics in the context of a broader experientially based story. Understandings of impact are primarily linked to approach, highlighting the importance of an appropriate and resonant message for the audience, emphasising collaboration and seeking to encourage people living with the virus to act as their own advocates. In contrast with some other groups studied TASO has a greater level of direct

cooperation with government and, as such, sees advocacy approaches that would threaten this relationship as being counterproductive.

Reflecting on the hypotheses put forward in Chapter 2, TASO does not match most of the expected criteria of an organisation that might employ rights as a primary frame. While some early founders did hold a rights orientation, the decentralised structure of TASO did not facilitate the spread of this frame to others in the organisation. Externally, the group exists in an environment where rights are not a dominant language of advocacy and, as such, this context could not provide support for a rights-based frame as occurred with TAC. As a domestically prominent organisation TASO has a number of donors, and is an attractive organisation to fund. These donors vary in their rights orientation, but have a limited influence on organisational frame. Organisational identity and niche are very much linked to constituency (people living with HIV) rather than frame. Impact is associated with techniques of advocacy rather than frames.

5.4 Rights Among Other Approaches: Conclusions

While diverse amongst themselves in many ways, groups using rights as one of several approaches indicate common features which distinguish them from the preceding chapter. In contrast to the strong belief in rights among rights dominant groups, and the use of rights as a broad perspective or worldview, groups in the rights mixed category were more likely to view rights as a topic, and one that applied to some campaigns but not others. NACWOLA respondents, for example, drew on numerous frames including rights, development, poverty alleviation and gender seeing each campaign as having particular characteristics with reference to frame. SAfAIDS while using both rights and development saw development as the broadest

possible frame and one which in itself was comprehensive enough to encompass most issues relating to HIV, while rights applied to specific topics, particularly domestic violence. TASO drew on its organisational values, which while including rights in several instances, focused on an organisational and personal experience of creating a positive and welcoming place where people with HIV were treated equally and with dignity. Among these organisations the idea of frame itself appeared somewhat less important than those in the rights dominant group, frequently subordinated to organisational identity or to the importance of a particular advocacy process.

Organisations in this category are, in two of three cases, membership and constituency-based groups who draw their organisational perspective and identity from this source. TASO and NACWOLA each have a core identity tied to people living with HIV/AIDS. As such, personal experiences are central to advocacy, informing the message and shaping how it is presented and by whom. Both groups have support as an important component of their organisational function and identity, referencing ‘family’ in discussion of their organisational character. Each organisation has a significant service provision component, although these services provided differ substantively, with TASO providing health care, SAfAIDS providing information and NACWOLA providing training and livelihood projects.

Among these groups rights were often encountered from external sources, and served to inform particular campaigns, but not to shift the perspective or frame of the organisation. These groups have a moderate level of international connection, although the number of personnel within each organisation that have direct international interaction varies significantly. Two of the three

organisations (NACWOLA and TASO) are large membership-based groups perhaps making it more difficult for leaders to influence the frame of the overall organisation.

While each of the groups conducts significant advocacy, often at a number of levels (local, national, regional, international) two of the three groups understand their position with reference to advocacy as being one of background preparation, support and capacity building with both SAfAIDS and TASO making comments about not wanting to be at the front of advocacy or, necessarily for it to appear in their name. Also in these two cases the method or process of advocacy is at times prioritised over frame, with dialogue or capacity building considered more important than the construction of the advocacy message. In several cases the nature and constituency of the organisation is highlighted as the key feature or niche of that group's advocacy, with NACWOLA emphasising their lived experience as women living with HIV and how that brings a different voice and emphasis to advocacy, and SAfAIDS highlighting their dispassionate policy approach. This differs from rights dominant groups who tended to place more emphasis on advocacy messaging, than on the distinctive voices of those communicating these messages.

One group, NACWOLA, suggests a possible intermediate step between smaller, less internationally connected and more support-oriented non-rights based groups and their larger more advocacy oriented rights-oriented counterparts. This group is described as having shifted from "sympathy-based" advocacy conducted in a more ad hoc fashion, to a clearer rights and advocacy orientation. If one understands this transition as a development stage, then NACWOLA may provide insight into the components and factors that lead to this shift. TASO and SAfAIDS, however, are both well-funded, well-established and internationally connected

organisations that do not fit this theory. The two groups have retained a diverse advocacy approach in which rights are not dominant despite clear exposure to these ideas and a long established advocacy function, and international rights-friendly donors. Interestingly, there is a significant amount of overlap in donors both among the groups in the mixed category as well as between these organisations and those with a dominant rights frame.

Reflecting on the hypotheses, these rights mixed cases suggest a few important findings and considerations. First, these cases suggest that leadership alone is not sufficient for organisational adoption of the rights frame, but that other factors including experience of personnel and organisational structure also play an important role. These three cases also indicate that organisational context is an important consideration and that networks and international linkages have the potential to be influential, but are unlikely to influence overall organisational frame, instead being more likely to affect specific campaigns. These linkages also indicate that rights are not contagious. That is to say groups can be exposed to rights, have allies using the rights frame, and have donors who support the rights frame, and yet not adopt this frame themselves. Finally, these cases indicate that the importance of frame may vary significantly. In contrast to rights dominant groups, the organisations in this category placed far less emphasis on frame with respect to organisational identity, organisational niche and impact instead highlighting target constituency or their advocacy techniques.

Chapter 6: Rights Limited: Avoiding or Limiting Rights References in Advocacy

While some groups lean heavily and deliberately on rights language, and others use it selectively or in concert with other frames, there are also organisations where reference to rights is limited, peripheral or even avoided. This chapter examines three very different organisations in which rights-based advocacy is limited or non-existent. The three groups: the National Association of People Living with HIV/AIDS Ghana (NAP+), Women United Against AIDS Ghana (WUAAG), and the Kuru Family of Organisation's Community Health Project in Botswana (Kuru), each score very low on the classification scheme outlined in the methodology chapter and are consequently categorised as 'rights limited.' While some reference to rights exists in each case, in none of these organisations is rights a prominent advocacy frame alone or alongside other frames. Among these groups reference to rights seldom occurred in print documents, was not mentioned as a campaign frame, and rights references rarely occurred without prompting in interviews.

Although the three cases examined here contain significant variation amongst themselves they also demonstrate important common themes. Several of these themes indicate an extension of features appearing in a more muted form among organisations in the rights mixed category. First, at the intra-organisational level groups in the rights limited category reflect a very narrow understanding of rights, viewing rights as a specific, limited and sometimes inaccessible concept. Experiential factors, particularly personal experiences of organisational members, are critical influences on the nature and form of advocacy, including its frame. Groups in this category are

more likely to be decentralised and membership-oriented in structure, often drawing personnel from the constituency groups they represent. Second, groups in this category generally have a lower level of international connection and are more likely to cite local influences on advocacy forms and frames. The three groups are not situated in domestic contexts where rights are a dominant advocacy frame. These organisations, however, have each been exposed to rights, each had international connections, and each had international donors some of whom favoured a rights-based approach. Finally, in all cases groups hold a niche and identity tied to the groups of people they represent and reflect that identity strongly in their advocacy. Impact is understood primarily as linked to the sharing of personal stories through testimony and to emphasising the vulnerability of those living with HIV and the effect of policies or behaviours on their lives.

As a whole, organisations that conduct HIV advocacy but do not refer readily to human rights were more difficult to identify than those that do. Even among groups with little reference to rights, limited understanding of rights or, an actual aversion to rights discourse, no group was encountered in this study that had absolutely no reference to rights in any form in any type of organisational document, report, or interview. When specifically questioned in interviews, some respondents would say that they did refer to rights in their advocacy, even where, as in the cases included in this chapter, other materials and observation did not support this assertion.³³⁵ This seems to indicate that many respondents viewed rights as an appropriate or positive topic to be working on and perhaps even a subject that, when directly asked, they felt as though they ought to claim or be seen to be addressing.

³³⁵Nor did the fact that rights were not generally mentioned without probing in interviews nor included in individual description of the organisational mandate or activities.

This diverse group also illustrates some interesting cross-case themes. Groups which make limited or no use of rights language tended to have a higher emphasis on service provision *vis a vis* advocacy, were more likely to be support-group based or organisations of people living with HIV/AIDS, were likely to have fewer print materials, were less likely to have a website, and had lower levels of international connection. Groups with limited rights-orientation were also more likely to occur outside of Southern Africa and, of the countries studied, more likely to occur in Ghana.

The organisations examined in this chapter have reasons for the frames that they do choose as well as varying explanations for their non-emphasis of rights in advocacy. The choice not to choose rights is not, as noted earlier, the simple opposite of the choice to do so. The three rights limited groups offer a variety of explanations for not employing rights in advocacy including: a specific and limited understanding of rights within the organisation, limited awareness and understanding of rights among key constituents, and deliberate avoidance of rights rhetoric due to unhelpful associations in the domestic context. The three cases examined here are presented in order along a spectrum from a perspective of limited use to actual avoidance. These cases present a continuum from the last chapter beginning with a group that demonstrates some indication of rights use in some parts of the organisation, albeit overshadowed by other approaches, and ending with a group that makes a deliberate choice not to reference rights. As in previous chapters, these three organisations are examined with regard to frame classification, intra-organisational factors, extra-organisational factors and perceptions of impact. Process tracing of campaigns is then conducted to understand how these factors mesh in practice.

6.1 National Association of People Living With HIV/AIDS (NAP+)

“HIV doesn’t kill it is the stigma that kills”³³⁶

As a large network of support groups, NAP+ exists at both national and local levels simultaneously. At the local level it is understood primarily as a support-based organisation, while at the national level it is perceived as a pressure-group. In both settings, an anti-stigma approach is dominant, with respondents emphasising the need to dismantle stigmatising viewpoints through education and awareness, often utilising the presentation of personal testimonials to do so. In this group rights were referenced occasionally and with little elaboration in the head office, and virtually never among district-based respondents.

As a case NAP+ indicates an extension and augmentation of some of themes emerging in the rights mixed cases, with very little congruence with the hypotheses laid out in Chapter 2. First, at the intra-organisational level, personal experience, particularly experience of living with HIV and addressing stigma is the primary influence on advocacy rather than belief in or experience with the rights frame. The group, like others in this category, is decentralised and has a membership-based structure. Extra-organisational factors were rarely cited as influential by respondents, although the group is highly networked at the domestic level and has a moderate level of international connection. The organisation’s identity and niche are tightly linked to the group’s identity as an organisation by and for people living with HIV/AIDS. Perceptions of impact are tightly linked to the expression of personal experiences, with an emphasis on emotive,

³³⁶ Author’s interview, Employee 4, National Association of People Living with HIV/AIDS Ghana (NAP + Ghana), 17 February 2010, Tamale, Ghana

touching stories of stigma, ill health and subsequent strength. Compassion with suffering is viewed as a critical catalyst to change.

6.1.1 Frame

NAP+ is an organisation with a significant difference in character between the national office and its regional presence in Tamale in the Northern Region.³³⁷ Locally, support is the group's most important function, while advocacy plays a stronger role at the national level. In both settings, the most prominent frame is that of stigma reduction, with limited reference to rights. NAP+ illustrates a 'weak mixed' approach among head office respondents, where some use of rights was mentioned by some respondents in combination with other approaches, while rights featured in responses by district-level respondents.

In the organisation's capabilities statement rights occur in two locations but are subordinate to concepts of stigma reduction and support. Rights are referenced in the vision where it is stated that NAP+ works to ensure people living with the virus "enjoy the same rights" as others as well as in the listing of programmes and activities where advocacy "for the rights of members" and "on human rights violations" are mentioned (NAP +, 2005, 1). In interviews rights references were not prominent, had limited elaboration and were rarely unsolicited. Two respondents at the national office listed rights as an important approach, one in combination with gender and the other in combination with combating stigma and discrimination. In all interviews there were frequent references to stigma and discrimination. Among Tamale respondents dominant frames

³³⁷ NAP+ has a presence in all ten regions of the country, however, interviews were only carried out in the national office and in one region: Tamale in the Northern Region.

of understanding were: (1) stigma and discrimination, and (2) compassion, care and support. Among these respondents rights were only referred to un-probed by one respondent. At the head office only one respondent made regular reference to human rights throughout the interview, including the use of the frame in advocacy messaging. No respondent referred to the group as a human rights organisation, and the primary understanding of the organisation was rooted in the group's identity as an organisation of people living with HIV/AIDS.

Although the group does not have a formal slogan, the most often repeated phrase, which appeared in three interviews in near identical form was "HIV doesn't kill; it is the stigma that kills." One respondent elaborated "when you stigmatise against me – it's a problem to me, but the virus is not a problem because I'm on treatment."³³⁸ Thus respondents largely conceived themselves as group working against HIV stigma, with the problem identified as stigma rather than HIV infection. The group had a limited number of self-produced documents, and no visible internally-produced posters or other wall materials. Those displayed, however, emphasised key themes that also emerged from interviews, such as testing, discrimination and increased involvement and empowerment of people living with HIV.³³⁹

³³⁸ Author's interview, Employee, NAP+ Ghana, 18 February 2010, Tamale, Ghana.

³³⁹ Four posters were displayed in the NAP+ Ghana national office boardroom, as observed in February 2011. These included an ActionAid Ghana poster entitled, "Do you take this man to be your lawfully wedded husband... I don't" primarily addressing domestic violence, "Forum virtual: adolescents y Jovenes Carrito por la vida" (no source listed, graphically highlighting testing), "Discrimination: If it doesn't raise your blood pressure, get a check up (Pan American Health Organisation), and the Vientiane Statement of Commitment on the Greater Involvement and Empowerment of People Living with HIV (Vientiane, Lao, PDR, 9 May 2008, UNDP).

6.1.2 Intra- Organisational Factors Affecting Frame Selection

“It is not a death sentence -- we are now living positive lives”³⁴⁰

NAP+ is a nationwide network of 336 support groups, with 10 regional branches and 14 staff in the national secretariat.³⁴¹ Founded in 2005 by the coming together of support groups in order to represent people living with HIV/AIDS in the national response, the group ran into some challenges in its earlier years, with many key leadership and staff leaving the organisation in 2007. Nonetheless, the group continues to operate actively with new leadership. The current governing executive council consists of one person from each of the ten regions plus the president, vice president and treasurer. Representing over 240,000 people living with HIV NAP+ is, according to organisational documents, “the largest advocacy group in Ghana” (NAP + 2005, 1). The organisation’s mission states that NAP+ “exists to improve the quality of life of all persons living with HIV/AIDS and protect the nation of Ghana from further infection through advocacy; information sharing; leadership; capacity strengthening and other relevant strategies and intervention” (NAP + 2005, 1). The vision elaborates that the group aims to work with other relevant groups to “ensure that [People Living with HIV/AIDS] in Ghana enjoy the same rights, opportunities and responsibility (sic) as everyone else without discrimination” (NAP + 2005, 1).

The organisation conducts a wide array of activities including: advocacy, capacity-building, education, and service provision. Advocacy is undertaken “for the rights of its members on human rights violations, gender equity, social injustice of stigma/discrimination and Treatment Access with quality health care, information education and communication” (NAP +, 2005, 1)

³⁴⁰ Author’s interview, Employee, NAP+ Ghana, 12 February 2010, Accra, Ghana.

³⁴¹ Interviews were carried out with three members of the national secretariat in Accra and with three NAP+ members in Tamale, Northern Region.

Capacity-building of member groups including training, education around behaviour change and adherence, it also includes the support of the creation of income generation activities. Education is both inward and outward-oriented including peer education, and general community education about the transmission of HIV. Stigma reduction is a significant focus of educational initiatives, with numerous respondents referring to presentations to communities, churches and mosques based on personal testimony and sometimes including the option to test. Finally, the group provides services including counselling and testing, prevention of mother to child transmission, adherence counselling and psychosocial counselling, condom distribution, care and support for its members, home-based care, and care for 700,000 orphans and vulnerable children.

6.1.2.1 Perspectives of Personnel

Significant variation exists between perspectives on advocacy frames and organisational purpose among personnel in the Accra headquarters and those in Tamale. All respondents interviewed were in leadership positions at either the national or regional level and had been involved with the group for a number of years, some since NAP+'s inception. Several respondents ran their own support groups in addition to their positions within NAP+. Members who commented on how they came to the group explained that they were referred to NAP+ affiliated support group at diagnosis, or that they came to NAP+ through a local support group that they joined seeking support and information.

Recurrent themes among Tamale respondents regarding organisational purpose included bringing people together for mutual support and advocating by talking to community leaders and groups. One respondent reflected the group existed "to bring people living with HIV together

and let them go out and advocate to people.”³⁴² The importance of coming together was highlighted by respondents who frequently recounted personal anecdotes relating how they joined NAP+ and what the organisation had done for them and others. Respondents often commented that the organisation had had a significant impact on their lives, providing support and allowing them to connect with others with similar life experience. Advocacy was also understood as an important activity, with one respondent noting that the organisation aimed “to make advocacy, to come together so that we can solicit funds to make our advocacy to reduce stigma and then new infections.”³⁴³ Personal experiences were understood as the basis of both the content and method of advocacy. The issue of stigma was often communicated to the public through personal testimony where presenters living with HIV tried to “touch” the audience and “give [...] them some feeling in the heart”³⁴⁴ by sharing their own stories, but also implicitly or explicitly showing how the audience could find themselves in the same situation and should learn their status.

Only one of the three Tamale respondents referred to rights, adding that they “make advocacy on care and support and then our rights [to] universal access and then free treatment” subsequently elaborating that they aimed for all Ghanaians to know their HIV status by 2015 “without fear or discrimination” and for treatment to be free or covered through national health insurance.³⁴⁵ In addition to access to services, this objective highlights some of same stigma-oriented themes evident in personal testimonials emphasising the need to counter discrimination and to increase the number of people who know their status. The two other respondents offered more

³⁴² Author’s interview, Employee 1, NAP+ Ghana 17 February 2010, Tamale, Ghana.

³⁴³ Author’s interview, Employee 2, NAP+ Ghana, 17 February 2010, Tamale, Ghana.

³⁴⁴ Author’s interview, Employee 1, NAP+ Ghana, 17 February 2010, Tamale, Ghana.

³⁴⁵ Author’s interview, Employee 2, NAP+ Ghana, 17 February 2010, Tamale, Ghana.

knowledge-oriented objectives of advocacy such as “to create awareness about HIV” and encourage people to test early³⁴⁶ and to “go to the people and talk to them because they are not informed.”³⁴⁷

Respondents from the national headquarters were far more likely to view NAP+ as primarily advocacy-oriented with fewer references to support and community. One respondent remarked that, “the bottom line is NAP+ is an advocacy group and also a pressure group so we try to influence decisions and policies by government and that is our business.”³⁴⁸ While in Tamale rights were seldom raised unless probed, in Accra rights references were occasionally offered. In both settings rights were understood as having a specific and limited meaning usually grounded in law and directly linked to legal recourse. The term rights itself was frequently understood as being a near synonym for specific enforcement mechanisms such as the Women and Juvenile Unit of the Ghana Police (WAJU) and Commission for Human Rights and Administrative (CHRAJ) and directly linked to recourse. Rights were also commonly understood to include responsibilities, with two respondents referencing the responsibility not to infect others when asked about rights. One respondent, for example, answered a question about how the organisation used rights by explaining that CHRAJ would be invited to speak to NAP+ members and would “tell us what we are not supposed to do.”³⁴⁹ Listed advantages of rights included being able to access legal recourse for events such as being fired or evicted due to HIV status. Another respondent when asked about advantages of a rights approach stated, “at least there are laws in Ghana in our Constitution protecting people living with HIV/AIDS but we have

³⁴⁶ Author’s interview, Employee, NAP+ Ghana, 18 February, Tamale, Ghana.

³⁴⁷ Author’s interview, Employee 1, NAP+ Ghana, 17 February 2010, Tamale, Ghana.

³⁴⁸ Author’s interview, Employee 2, NAP+ Ghana, 10 February 2010, Accra, Ghana.

³⁴⁹ Author’s interview, Employee 1, NAP+ Ghana, 17 February 2010, Tamale, Ghana.

reinforced those laws.”³⁵⁰ Although rights did not feature as a common frame at NAP+, there were few specific reasons given to deliberately avoid the use of rights language. Disadvantages to the use of human rights that were listed included: frustrations with recourse mechanisms, protective laws that were not enforced, and “stepping on people’s toes.”³⁵¹ A single respondent made a comment linking rights language to outcomes, stating “we believe if we use a human rights approach we’ll get what we want.”³⁵² However, due to the understanding of rights sometimes being equated with enforcement mechanisms there was often a view that rights meant their successful claiming.

6.1.3 Extra-Organisational Factors Affecting Frame Selection

NAP+ does not exist in isolation and through its network structure has a high level of domestic interaction with groups, particularly at the grass roots level, as well as moderate levels of international involvement primarily affecting leadership in the national office. The group is very locally-grounded and did list local context as an influence on advocacy but did not tend to cite connections with other organisations as important influences on frame selection.

6.1.3.1 Domestic Factors

As a network of affiliated support groups NAP+ has a presence in all regions of Ghana. Those in leadership positions both in the national headquarters and in regional offices usually also lead local support groups providing NAP+ with an extensive grassroots network through these local groups. Other organisations within Ghana were not cited by respondents as holding influence on

³⁵⁰ Author’s interview, Employee 2, NAP+ Ghana, 10 February 2010, Accra, Ghana.

³⁵¹ Author’s interview, Employee 2, NAP+ Ghana, 10 February 2010, Accra, Ghana.

³⁵² Author’s interview, Employee 2, NAP+ Ghana, 10 February 2010, Accra, Ghana.

frame selection more generally, or with specific reference to rights. Some respondents did link current advocacy to early HIV preventions messages in Ghana. Respondents asserted that in these initial messages, the virus was directly equated with death, a message that some respondents felt had created the stigma against those living with HIV. Some current advocacy messages were constructed to respond to the information put out by these early messages emphasising that HIV is not “death warrant” or “death sentence” and with one respondent wanting to put his picture on a billboard in order to show people how strong and healthy a person with HIV can look. Rights-based advocacy is not a dominant form of advocacy in Ghana either in civil society overall, or the HIV sector.

6.1.3.2 International Factors

At the headquarters level, NAP+ is connected to other groups within and beyond the West African region. These interactions were listed as opportunities to learn new practices and methods of advocacy, but were not cited by respondents as a place where they were exposed to new advocacy frames such as rights. As an organisation, NAP+ is a member of the West African Treatment Action Group, the West African Network of People Living with HIV/AIDS, the African Network of People Living with HIV/AIDS, and the Global Network of People Living with HIV. Members of the organisation have been trained by the Treatment Action Group (US) and the International Community of Positive Women – Uganda. These training workshops were reported as important in strengthening skills and morale. One respondent reflected that “these trainings build my capacity to become a community activist.”³⁵³ She elaborated that training workshops were an experience from which she drew strength, commenting “it’s the training that

³⁵³ Author’s interview, Employee 1, NAP+ Ghana, 10 February 2010, Accra, Ghana.

makes me very strong.”³⁵⁴ Another respondent commented that interactions such as these had imparted specific advocacy-related strategies including the need to back claims up with numbers and the utility of consulting stakeholders.

NAP+ has some linkages with related international groups beyond the African continent though the degree of personal interaction with these networks varied considerably from the national office to regional levels. The group’s President had attended the Toronto (2006) and Mexico (2008) world AIDS conferences, having had a display at the latter, and planned to attend the 2011 Vienna Conference. One respondent remarked that the “President ha[s] gone to so many countries.”³⁵⁵ One other respondent had travelled to South Africa for a training workshop through an organisation called Grassroots Sisterhood. She explained that she went “to learn best practices from others [about] how they are able to organise home-based care” adding that she met people from all over Africa and learned about the situation in countries with higher prevalence rates as well as about micro finance.³⁵⁶ Like other organisations, NAP+ has also had international staff – another source of potential exposure to new ideas and advocacy frames. One respondent noted that the group had recently had an international staff member from the Japanese Embassy who had built organisational capacity primarily in the area of book keeping and proposal writing. The organisation periodically had international volunteers in the head office, with one respondent reporting an objective to increase the number of such volunteers. No link was made between international volunteers and advocacy frame, with greater emphasis placed on administrative and other skills.

³⁵⁴ Author’s interview, Employee 1, NAP+ Ghana, 10 February 2010, Accra, Ghana.

³⁵⁵ Author’s interview, Employee 2, NAP+ Ghana, 17 February 2010, Accra, Ghana.

³⁵⁶ Author’s interview, Employee 2, NAP+ Ghana, 17 February 2010, Tamale, Ghana.

6.1.3.3 Donors

Most of NAP+'s funding sources were international in origin including several donors that also fund groups in the rights dominant and rights mixed categories. NAP+'s donors have a variety of preferred frames, including development, rights and public health. When asked to list donors respondents mentioned the Stephen Lewis Foundation (Canada), technical support from UNAIDS, the Netherlands Embassy (through the Ministry of Local Government), United States Agency for International Development (USAID), Department for International Development (DFID, UK), Catholic Relief Services (CRS), Action Aid, and Academy for Educational Development's Strengthening HIV/AIDS Partnerships programme (AED SHARP). Domestically, the Ghana AIDS Commission was also listed as a source of funding. Of the funders listed, AED SHARP was cited as the major donor. This USAID-funded project states its purpose as being to "seek [...] to use an evidence and researched-based approach to identify most-at-risk groups, understand their needs, and develop targeted interventions based on these results" (AED website).

Respondents did not suggest connections between preferred donor frames and organisational frame in interviews, instead emphasising NAP+'s important membership of people living with HIV. One respondent noted that "HIV also brings business for plenty people" and that "some people took money intended for care and support" but that "NAP+ is a real organisation with the real people."³⁵⁷ Respondents indicated concern about the level of funding for HIV initiatives in Ghana, noting that some donors are ceasing to fund groups of people living with HIV/AIDS. Representing this constituency and seeing the involvement of people living with HIV/AIDS as

³⁵⁷ Author's interview, Employee 2, NAP+ Ghana, 10 February 2010, Accra, Ghana.

critical, one respondent asserted that NAP+ was “chasing [the funding] back” in Ghana, asking “do [donors] want HIV to come down or do they want it to go up?”³⁵⁸ With a diverse group of funders with varying foci, a clear link between donor objectives and organisational activities and approaches was difficult to make. Interestingly, however, a 2008 Organisational Assessment Report encouraged the alignment of organisational objectives with donor priorities.

6.1.4 Impact

*“giving human face to the disease”*³⁵⁹

The link between strategies and successful advocacy was articulated by most respondents with several emphasising particular ways of phrasing or presenting information. Factors listed as being important in successful campaigns included dialogue, which one respondent noting, “there’s no point where dialogue has failed.”³⁶⁰ Other strategies that were emphasised included having facts and figures, being able to mobilise people, being able to communicate messages on a personal level and ongoing interaction. Use of language was highlighted by several respondents. The importance of language which “touches the heart”³⁶¹ in giving testimony about personal experience was given heavy emphasis, with respondents strongly highlighting need and vulnerability as a key features in successful advocacy. Respondents described two main topics of advocacy, one carried out at a community-level which involved combating stigma and discrimination and one national level involving access to medication including a past campaign against drug stockouts and a current campaign at the time of interviews for free anti-retroviral medication.

³⁵⁸ Author’s interview, Employee 1, NAP+ Ghana, 10 February 2010, Tamale, Ghana.

³⁵⁹ Author’s interview, Employee 2, NAP+ Ghana, 10 February 2010, Accra, Ghana.

³⁶⁰ Author’s interview, Employee 2, NAP+ Ghana, 10 February 2010, Accra, Ghana.

³⁶¹ Author’s interview, Employee 1, NAP+ Ghana, 17 February 2010, Tamale, Ghana.

6.1.4.1 Campaigns

6.1.4.1.1 Anti-Stigma Advocacy

The community-level campaign addressing stigma and discrimination was referred to extensively by respondents in both Accra and Tamale. Tamale respondents saw this ongoing campaign as the central component of the organisation's work. Respondents described presentations, often centred on personal testimony delivered to "community leaders, opinion leaders, traditional leaders, religious leaders"³⁶² as well as to churches, mosques, and schools. Central messages to this campaign included HIV awareness highlighting modes of transmission and the importance of early testing, "giving human face to the disease"³⁶³ through personal stories, emphasising that "it's not a curse"³⁶⁴ and that if you are positive it doesn't mean it will be the end of your life."³⁶⁵ This campaign also included the message that, as HIV is not visible it could infect, or may already have infected those who know or who assume themselves to be HIV negative. One respondent remarked, for example: "they should stop stigma because you don't know if it is me with HIV, maybe tomorrow it'll be you and [if] we don't stop stigmatising and tomorrow it is you – you won't survive."³⁶⁶ Testimonies were often delivered with a nurse present so that participants could test for the virus following the presentation.

Several respondents spent considerable time describing how to shape the message in order to have an impact. The importance of personal stories was highlighted by many as a way to show HIV positive people as human, healthy and relatable. One respondent noted, "if you just put it anyhow, it will not touch the fellow's heart ... you put it somehow that there will be sympathy in

³⁶² Author's interview, Employee, NAP+ Ghana, 18 February 2010, Tamale, Ghana.

³⁶³ Author's interview, Employee 2, NAP+ Ghana, 10 February 2010, Accra, Ghana.

³⁶⁴ Author's interview, Employee 2, NAP+ Ghana, 10 February 2010, Accra, Ghana.

³⁶⁵ Author's interview, Employee, NAP+ Ghana, 18 February 2010, Tamale, Ghana.

³⁶⁶ Author's interview, Employee, NAP+ Ghana, 18 February 2010, Tamale, Ghana.

the message. For [an] HIV message there has to be sympathy inside,” however, if presenters are able to strike the right chord it may “touch them ... give feeling in the heart, some people even cry.”³⁶⁷ These messages, usually beginning with surprise (“you are HIV positive!”)³⁶⁸ followed by a moving story of extreme illness, pain and isolation, and culminating with a story of recovery, usually involving anti-retroviral drugs were reported to inspire, solicit donations, encourage those living with the virus (“if they are weak and lying down one day they will become like you”)³⁶⁹ and break down stigma, with one respondent noting that following presentations “some are able to eat with you.”³⁷⁰ Personal connections were considered to play a very important role in stigma reduction.

Although the anti-stigma campaign is very broad, and NAP+ is not the only group working in this area, respondents felt that there had been a real change in their communities with respect to stigma and felt that NAP+ had played a role in this. One respondent felt that the “mere presence [of] a support group is doing a lot of change in communities” noting “that’s another [advocacy] approach and it’s very powerful.”³⁷¹ As an example of the power of “mere presence,” several respondents in the NAP+ National Office noted that when the organisation first moved to their current office “people were not using [the] road” their office was located on due to stigma.³⁷² Subsequently, however, people in the neighbourhood “started asking questions” and now

³⁶⁷ Author’s interview, Employee 1, NAP+ Ghana, 17 February 2010, Tamale, Ghana.

³⁶⁸ Author’s interview, Employee 1, NAP+ Ghana, 17 February 2010, Tamale, Ghana.

³⁶⁹ Author’s interview, Employee 1, NAP+ Ghana, 17 February 2010, Tamale, Ghana.

³⁷⁰ Author’s interview, Employee 1, NAP+ Ghana, 17 February 2010, Tamale, Ghana.

³⁷¹ Author’s interview, Employee 2, NAP+ Ghana, 10 February 2010, Accra, Ghana.

³⁷² Author’s interview, Employee 2, NAP+ Ghana, 10 February 2010, Accra, Ghana.

“people are even coming in to get condoms, have conversations, to interact with us.”³⁷³ He added, “indirectly we are changing the community with our presence.”³⁷⁴

Several respondents noted an overall decrease in stigma, with one person noting “we are getting to something”³⁷⁵ and another contrasting the current situation where she can “go to communities to educate people” to the killing of a woman in South Africa who was open about her status.³⁷⁶

Other respondents commented that in the last five years there had been “drastically tremendous change” and that 5 years ago “it would have been difficult to have a [Person Living with HIV/AIDS] to interview.”³⁷⁷ Another respondent asserted that stigma has reduced “unlike those days” when people would offer a stick to someone with HIV rather than their hand in order to help them to stand up.³⁷⁸ One woman explained that things had improved because now if she faced discrimination she would go to the relevant state institutions to have the situation rectified.

While the impact of anti-stigma campaigns were primarily outward-oriented several respondents also commented that they had had a strong personal impacts and that they, through their involvement with NAP+ had changed dramatically. One respondent described her experience:

I used to be always like this [slumped, head hanging] thinking, worried....thinking when am I going to die... but now I don't have those things, I'm always happy. We join together go to workshops, we dance, we do everything.³⁷⁹

Respondents on several occasions highlighted their physical strength and reflected proudly on their ability to act independently and to live active lives.

³⁷³ Author's interview, Employee 2, NAP+ Ghana, 10 February 2010, Accra, Ghana.

³⁷⁴ Author's interview, Employee 2, NAP+ Ghana, 10 February 2010, Accra, Ghana.

³⁷⁵ Author's interview, Employee 1, NAP+ Ghana, 17 February 2010, Tamale, Ghana.

³⁷⁶ Author's interview, Employee 1, NAP+ Ghana, 17 February 2010, Tamale, Ghana.

³⁷⁷ Author's interview, Employee 2, NAP+ Ghana, 10 February 2010, Tamale, Ghana.

³⁷⁸ Author's interview, Employee 1, NAP+ Ghana 17 February 2010, Tamale, Ghana.

³⁷⁹ Author's interview, Employee 1, NAP+ Ghana, 17 February 2010, Tamale, Ghana.

Although stigma is a concept very easily linked to human rights, human rights did not appear in descriptions of this campaign. Respondents placed heavy emphasis on the importance of personal stories, in the form of testimony, and personal interactions in decreasing stigma. They generally tried to connect with their audience on a personal, emotional level, calling to compassion and for the audience to see themselves in the shoes of someone living with HIV, rather than to concepts of rights or obligation.

6.1.4.1.2 Access to Anti-Retroviral Drugs

NAP+ respondents made mention of two related campaigns dealing with access to anti-retroviral medication. The first campaign involved drug stockouts, while the second campaign, ongoing at the time of interviews, dealt with trying to eliminate the five *cedi* monthly charge for anti-retroviral medications.³⁸⁰ These two campaigns were raised exclusively by respondents in the national office in Accra.

The first campaign was described as originating from a situation where access to ARVs was becoming limited, with individuals only able to get a one week supply at a time (instead of the usual one month). A petition was taken to the Minister of Health, and the issue was raised with the President. One respondent framed the issue as one of rights noting that people with HIV have “the right to access, right to treatment, right to everything” elaborating “we know everybody in Ghana [has] the right of health and ARVs is one of our health [rights] to people living with HIV/AIDS.”³⁸¹ Other respondents, however, framed the campaign as one centred on need,

³⁸⁰Approximately Cdn \$3.15 as of 11 July 2011 .

³⁸¹Author’s interview, Employee 1, NAP+ Ghana, 10 February 2010, Accra, Ghana.

arguing “we don’t want a time when the drug will be short because this is a lifetime something” for people living with HIV.³⁸² The drug supply was rectified and within a short time respondents reported “the drugs [were] here.”³⁸³ When asked what made this campaign a success, a number of factors were cited:

we had a case to present and it was a genuine case because it concerns the life of people and therefore the then government was also very passionate so I would say the government position was quite clear and it was in support of the [People Living with HIV/AIDS]. Government was quite passionate about treatment and care and so it wasn’t very difficult for us to petition him to wake up to the call – so government was there for us and the then Minister was also very ready and so we had it very easy and out leaders were also very committed as well as our members. Because it’s not easy here in Ghana to demonstrate people to be captured on television most especially the [People Living with HIV/AIDS]s and so the community members... and so it was successful and so both government and the [People Living with HIV/AIDS] community were both ready and so the readiness level for both sides were there so it worked.³⁸⁴

In this situation the confluence of a “genuine” case and organised membership and a responsive government made advocacy possible and productive.

NAP+ is also involved in a current campaign to remove the 5 *cedi* monthly charge for anti-retroviral medication under the new national health insurance program which fully covers medications for many other conditions. Arguments given for the removal of this fee were predominantly based around need for the drugs and the inability to pay for them. When asked why the government should remove fees respondents commented “so that the [People Living with HIV] can benefit ... because if they put on the drug those of us are not sick again.”³⁸⁵ Respondents also highlighted issues of poverty and unemployment, commenting “our people

³⁸² Author’s interview, Employee 2, NAP+ Ghana, 10 February 2010, Accra, Ghana.

³⁸³ Author’s interview, Employee 1, NAP+ Ghana, 10 February 2010, Accra, Ghana.

³⁸⁴ Author’s interview, Employee 1, NAP+ Ghana, 10 February 2010, Accra, Ghana.

³⁸⁵ Author’s interview, Employee 1, NAP+ Ghana, 10 February 2010, Accra, Ghana.

cannot afford to pay”³⁸⁶ elaborating “we have lost our homes, we have family to care [for] and we are not working.”³⁸⁷ Other arguments offered included government accountability for money that went into health insurance and for the five *cedis*, and equity among health conditions. According to respondents various actors were being pressured including UNAIDS and other development partners and several government agencies including the Ghana AIDS Commission and the Ministry of Health, with one respondent noting that the issue was currently being debated and discussed. However, as of November 2012, the national health insurance continues to include anti-retroviral drugs on their exclusions list (Daily Graphic 2012). This campaign focused primarily on need, highlighting the known benefits of the drugs, the general inability of people living with HIV/AIDS to afford them and the impact of not being able to access the drugs.

6.1.5 Conclusions: NAP+

Although some respondents at the national level mentioned rights, in practice descriptions of organisational activities, campaign and documents highlight the organisation’s primary identification as a network of people living with HIV/AIDS who exist primarily to provide support and counter stigma. The oft-repeated phrase “HIV doesn’t kill but stigma does,” identifies stigma as the key obstacle, shifting the emphasis away from the virus itself. At both national and local levels the importance of personal stories and interactions was highlighted as the critical catalyst for social change. Campaigns made an attempt to ‘show a human face’ to translate abstract concepts into human experiences through testimony, and through demonstrated

³⁸⁶ Author’s interview, Employee 1, NAP+ Ghana, 10 February 2010, Accra, Ghana.

³⁸⁷ Author’s interview, Employee 2, NAP+ Ghana, 10 February 2010, Accra, Ghana.

need and vulnerability. In contrast, rights were generally raised only when probed, and were understood as limited legal constructs which related directly to enforcement mechanisms.

Reflecting on the hypotheses, NAP+ demonstrates few of the factors associated with rights choosing. Internally, personal experiences centering on stigma are highlighted. The organisation is highly decentralised, but united through lived experience with the virus and its social consequences. This structure facilitates some variation in perspective, with rights mentioned occasionally in the headquarters' setting but virtually absent in Tamale. Externally, NAP+ does not exist in a rights oriented environment, and relates more to local contextual factors than to the practices of other domestic or international organisations. These two factors in combination suggest that in an environment where rights are not locally dominant it may be difficult to maintain a strong rights orientation with a decentralised organisational structure. International connections are primarily at the level of headquarters. However, the group has clear exposure to rights language, and does have some rights oriented donors. Organisational identity and niche are strongly tied to NAP+ being a group by and for those living with HIV. Finally, impact is associated with very personal expressions of stigma and suffering employing these difficult experiences to make emotional links with others and, through that, invoke changes in behaviour.

6.2 Women United Against AIDS in Ghana (WUAAG)

*“United We Stand: Show Compassion”*³⁸⁸

Established in a response to marginalisation within other HIV support groups and experiences of societal rejection and isolation, Women United Against AIDS in Ghana (WUAAG) has become

³⁸⁸Organisational Slogan, WUAAG 2002.

a home away from home for many of its members. Growing out of experiences of isolation, the group emphasises solidarity and mutual support as well as staying very clearly women-centred. The group's advocacy focuses on messages of need and compassion, often highlighting consequences of inaction on the health or life of its members. Although rights are referred to occasionally, they are understood and articulated in a limited legal sense and are not the primary frame through which the organisation, its objectives, or campaigns are understood. The group is relatively small, with connections to local and national HIV NGOs, and periodic international connections mainly in the form of travel to conferences and training courses by the group's President.

As a case WUAAG does not exhibit many features as identified through the hypotheses that would be expected of a rights oriented group. At the intra-organisational level lived experience plays the most important role in shaping how WUAAG conducts advocacy. The organisation is relatively centralised but is membership-based with a membership consisting almost exclusively of women living with HIV/AIDS. Externally, the group is influenced by other domestic actors, has a relatively low level of international connection beyond the President and has a mix of domestic and international funding with preferences for a variety of frames. The group identifies strongly as a group of women living with HIV and sees this as its important organisational niche. Impact is understood to result from expressions of need, with most advocacy consisting of requests rather than demands.

6.2.1 Frame

*“Show Compassion”*³⁸⁹

WUAAG is clearly a women-centred organisation, with the group’s website describing WUAAG as “basically a women’s organisation” and emphasising a female membership (WUAAG website - Organogram – 2012). The group’s history also places emphasis on gender dynamics, however, the language of gender, or women’s rights does not feature prominently in the organisation’s materials or advocacy messaging. The group uses eclectic strategies in its advocacy campaigns, choosing messages based on the issue and often emphasising need and highlighting the impact of particular policies on their constituents. Within the group, experiential and membership-based advocacy was particularly emphasised. The organisation’s slogan “united we stand” is used as a greeting at meetings³⁹⁰ vocally emphasising solidarity and community. A secondary message also appearing in the organisation’s logo is “show compassion” communicating a message of acceptance, but also sympathy (WUAAG website – Home Page, 2012).

Human rights did not appear as a prominent frame within WUAAG. Rights were not mentioned in the organisational objective nor in the organisation’s pamphlet. On the website the term appears once under key areas of operation, where one of the seven areas is “[a]dvocating the promotion and uphold[ing] of the fundamental human rights of women living with HIV/AIDS and their families”(WUAAG website – Strengths, Weakness and Opportunities, 2012). Materials posted on the office walls did not generally feature a human rights message. Out of fifteen materials surveyed, one newspaper article highlighted human rights training provided to WUAAG. Placards shown in photographs on the organisation’s website, as well as placard

³⁸⁹Organisational slogan, WUAAG 2002.

³⁹⁰The greeting is done in a call and response fashion, one person saying “united” and the other/s responding “we stand.”

messages mentioned in interviews did not refer to human rights, instead drawing messages based on education (ie “AIDS is real: protect yourself”), sympathy-based messages (“Show Compassion”), and messages promoting acceptance (“Fight the Virus not the Person Living with HIV/AIDS”) (WUUAG website, 2012). In interviews, reflections on human rights were varied but appeared peripheral. In two of three interviews human rights were not mentioned by respondents until specifically asked by the interviewer. Respondents consistently viewed the organisation’s primary mandate as assisting women living with HIV. In relation to advocacy respondents gave varying responses, with a sole respondent viewing human rights-based advocacy within the organisation as central.

In describing the organisation’s objectives respondents placed primary emphasis on care and support for women living with HIV. One respondent elaborated that WUAAG existed for “the members to feel that they are part of our society”³⁹¹ with another respondent including children living with HIV and their caregivers in this group. A third respondent felt that the ultimate objective of the group included reducing HIV infections in the country. A single respondent made a link to rights stating that one of the organisational objectives was “empowering the women to be in a better position to advocate and enforce their rights as they have been guaranteed for them in the Constitution of Ghana.”³⁹²

³⁹¹ Author’s interview, Employee 2, WUAAG, 10 February 2010, Accra, Ghana.

³⁹² Author’s interview, Lydia Asante, WUAAG, 19 February 2010, Accra, Ghana.

6.2.2 Intra-Organisational Factors Affecting Frame Selection

“we started work under a tree we don’t have anywhere to go so we started under a tree”³⁹³

Founded in 2000 and registered in 2002 WUAAG is Ghana’s “first support group for women living with HIV/AIDS” (WUAAG 2002) and was created partly in response to the experience of women in male-dominated groups. Based in metropolitan Accra, the group consists of a six member executive council, all women “either infected with or [who] have been directly affected by HIV/AIDS” (WUAAG website, 2012), a three member secretariat which reports to the executive, and volunteers. Interviews were carried out with three employees. Volunteers have played important and integral roles within the organisation as “until 2007, there has been no funding to employ anyone even on a part-time basis” (WUAAG website, 2012). According to the website, the organisation has about 100 people involved in the organisation of whom 60 are registered members, 59 of whom are women (WUAAG website, 2012). The group describes its aim as:

to bring together women infected and affected by HIV/AIDS and their children to live a positive life of dignity; support and care for each other; and also provide a forum for the discussion of issues of common concern, most importantly, health, nutrition, economic and socio-cultural issues (WUAAG 2002).

These are based on four guiding principles: (1) “provision of care and support for women living with HIV/AIDS,” (2) [m]itigating economic, health, nutritional, cultural and psychosocial effect[s] of living with HIV/AIDS,” (3) “[p]romoting positive living among women and children living with HIV/AIDS,” (4) “[c]ontributing towards the prevention of the spread of HIV/AIDS among women and girls” (WUAAG website). The group provides support, small loans and income generation projects, care, and conducts some community education and advocacy.

³⁹³ Author’s interview, Employee 1, WUAAG, 10 February 2010, Accra, Ghana.

6.2.2.1 Personal Experiences and Needs

Personal experiences have played a critical role in the formation and development of WUAAG. Experiences of isolation, expulsion from family homes, and marginalisation within male-led support groups led to the group's inception. These experiences were often quite intense, with one respondent noting that upon sharing her diagnosis her family stated "what a disgrace."³⁹⁴ Some women lost their spouses to the illness, while others were shunned. These experiences of disconnection and forcible severing of family and relational networks pushed the organisation to fill these voids and operate almost as a surrogate family.

Forced isolation played a formative role in both the need for the organisation, as well as in its form and function. One respondent stated that "even now I don't go to my family house, I was rejected," adding that "because of this [diagnosis] I don't have a family" stating "WUAAG is my family."³⁹⁵ After her husband's death and her own diagnosis she felt separated and rejected by others, describing her thoughts at the time by saying "I am no longer a human being" and contemplating suicide.³⁹⁶ She eventually joined the country's first support group, Wisdom, and made friends with a woman who had been to Uganda and "found women's groups there and they were doing well" asking herself, "why can't I found one?"³⁹⁷ Along with friends she founded WUAAG, was joined by 5 women from the previous support group and subsequently recruited others from clinics. Making these connections, she noted "I became bold."³⁹⁸ Initially meeting

³⁹⁴ Author's interview, Employee 1, WUAAG, 10 February 2010, Accra, Ghana.

³⁹⁵ Author's interview, Employee 1, WUAAG, 10 February 2010, Accra, Ghana.

³⁹⁶ Author's interview, Employee 1, WUAAG, 10 February 2010, Accra, Ghana.

³⁹⁷ Author's interview, Employee 1, WUAAG, 10 February 2010, Accra, Ghana.

³⁹⁸ Author's interview, Employee 1, WUAAG, 10 February 2010, Accra, Ghana.

under a tree, the group gathered three times a week to avoid isolation and give purpose to their days and weeks. In addition to providing a sense of structure and belonging, the meetings served as a place of common experience where they were not “other,” with one respondent noting “they feel comfortable when they talk amongst themselves.”³⁹⁹

Experiences of marginalisation from the broader society pushed the group to emphasise collectivity, belonging and community in their activities and in the way in which they constructed their advocacy messages. Statements such as “we are also people and deserve equal opportunity with respect to healthcare”⁴⁰⁰ try to respond to feelings of separation. They emphasise a shared humanity, indicating that entitlements and opportunities from being human, or being a citizen, are not lost through diagnosis. The group identified two forms of advocacy, one outward oriented and one inward oriented. The first form of advocacy is directed outward and aims to educate the general public about HIV (ie ‘it is real,’ ‘it is not a curse’) and to encourage tolerance and compassion. Initiatives in this area included an educational radio programme and testimonials of personal experience. The second form of advocacy was described as including information about recourse for rights violations and initiatives aimed at eliminating self-stigma, focusing on messages of strength and solidarity. These messages were described as needing to be “very practical, not abstract.”⁴⁰¹ One respondent referred to rights-based messages used in internal advocacy, noting that:

Every time [members] succeed in enforcing their right they share and they come to the meeting and they laugh! Somebody’s landlord was trying to throw her out because of her status so she threatened to have him arrested and prosecuted for discrimination. The landlord didn’t know what she was talking about but the fact that she said it – she knew

³⁹⁹ Author’s interview, Employee 2, WUAAG, 10 February 2010, Accra, Ghana.

⁴⁰⁰ Author’s interview, Lydia Asante, WUAAG, 19 February 2010, Accra, Ghana.

⁴⁰¹ Author’s interview, Lydia Asante, WUAAG, 19 February 2010, Accra, Ghana.

her rights. She used the phrase “I know my rights, and if you try it I’m going to get you arrested.” She was able to succeed and she’s still living in that house.⁴⁰²

This message of resilience is nested within strength in the collective, and an ability to articulate belonging in the system. One respondent commented that a key purpose of the organisation was “for [women living with HIV] to feel that they are part of our society”⁴⁰³ including, as above, the ability to access and use language and mechanisms of recourse.

6.2.2.2 Membership and Volunteers

Members were seen as strongly influencing areas of work, with a respondent explaining that “a lot of issues that we work on are issues that the members themselves come to me and talk to me about” adding that campaigns have been spurred by membership questions.⁴⁰⁴ Two respondents commented that active campaigning was at times difficult due to concerns about confidentiality and some members not wanting to be identified as HIV positive. Apart from founding members, members tended to come to the organisation by referral from the Korle Bu Teaching Hospital, and through friends who were already members. Over time the group has been bolstered periodically by interns from the University of Ghana’s Department of Social Work and the Department of Social Work from the government, which may have placed an emphasis on social work approaches. Volunteers interviewed came to the group through personal and career connections, bringing with them backgrounds in the areas of health and law.

⁴⁰² Author’s interview, Lydia Asante, WUAAG, 19 February 2010, Accra, Ghana.

⁴⁰³ Author’s interview, Employee 2, WUAAG, 10 February 2010, Accra, Ghana.

⁴⁰⁴ Author’s interview, Lydia Asante, WUAAG, 19 February 2010, Accra, Ghana.

6.2.3 Extra-Organisational Factors Affecting Frame Selection

6.2.3.1 Domestic Factors

WUAAG is influenced by several domestic factors in its emergence and operations. The group emerged to fill a void – that of a women’s HIV support group. WUAAG received early leadership from the Society of Women and AIDS in Africa – Ghana (SWAA- Ghana), with one respondent noting that “SWAA is like our mother.”⁴⁰⁵ The organisation is also a member of the National Association of People Living with HIV/AIDS – Ghana (NAP+) and, lists one of its key areas of operation as “networking with other support groups for PLWHA [People Living with HIV/AIDS]” (website, key areas of operation). However, NAP+ was not seen as a critical influence with one respondent noting “NAP+ is there but we are not seeing anything, the name is there.”⁴⁰⁶ As noted earlier, rights are not a dominant language of advocacy in Ghana.

Social work students from the University of Ghana and the Department of Social Welfare periodically undertake placements at WUAAG. At the time of interviews, the organisation also had a University of Ghana law student playing a key role within the organisation. No comments were made about any of these groups or individuals influencing the approach of the group either towards or away from human rights.

Respondents did not comment on the organisation being in competition with others groups domestically and felt the organisation was unique in several ways. Two respondents felt that the group’s transparency made it stand out, with one noting “because of the transparency we are

⁴⁰⁵ Author’s interview, Employee 2, WUAAG, 10 February 2010, Accra, Ghana.

⁴⁰⁶ Author’s interview, Employee 2, WUAAG, 10 February 2010, Accra, Ghana.

going higher and higher.”⁴⁰⁷ Others mentioned distinct activities such as soft loans, explaining that “no other group is doing what WUAAG is doing.”⁴⁰⁸ No respondents made reference to advocacy or advocacy strategies when describing the organisation’s unique niche, instead referring to the group’s special position as an organisation by and for HIV positive women.

6.2.3.2 International Factors

International connections have played an important but not central role in the organisation’s history, with their impact tending to be limited to the President. As stated earlier, an international connection sparked the idea for the organisation’s formation, empowering the women who founded WUAAG to build an organisation run by and for women living with HIV. The President’s office has walls liberally dotted with certificates of participation in international conferences, with her listing travel to Spain, Mexico, Toronto, India, Nigeria, Senegal, Sudan, and Sierra Leone. One respondent explained that through travel new ideas had been encountered, listing mushroom farming as an income generation project as one example.⁴⁰⁹

A survey of wall materials found posters and other documents from South Africa (TAC) and the United States (Black Coalition on AIDS). A newspaper article was posted about human rights-related training for women living with HIV sponsored by the Canadian International Development Agency. The group has also participated in several World AIDS Conferences over the years with WUAAG’s President given an award at the Barcelona conference in 2002.

⁴⁰⁷ Author’s interview, Lydia Asante, WUAAG, 19 February 2010, Accra, Ghana.

⁴⁰⁸ Author’s interview, Employee 1, WUAAG, 10 February 2010, Accra, Ghana.

⁴⁰⁹ Author’s interview, Employee 2, WUAAG, 10 February 2010, Accra, Ghana.

At the time of interviewing WUAAG consisted entirely of Ghanaian staff and volunteers, though their website states that “periodically, other students from universities abroad have assisted and participated in the activities of WUAAG as volunteers” (WUAAG website – Organogram, 2012). Respondents also showed me a photo on a bulletin board of a Canadian woman who had been involved with WUAAG and referred to the work of three American volunteers.

6.2.3.3 Donors

WUAAG began in 2000, and was registered in 2002, but did not receive significant funding until 2007. Early funders included African Women’s Development Fund (AWDF), which focuses on women’s empowerment and development, with some reference to rights, and Hope for African Children Initiative (HACI) which is child-centred. Pro-Link, a group focusing on socio-economic disadvantage and rights was also cited by one respondent as being an important early supporter. Current international funders include: AWDF, HACI, Catholic Relief Service, Global Fund for Women, Canadian International Development Agency, North American Women’s Association, and Opportunities Industrialisation Centre International (OICI). Domestically, the group is supported by the Ghana AIDS Commission, the National AIDS Control Programme, Rescue Mission Ghana, Nugouchie Memorial Medical Research Institute – University of Ghana, Coca-Cola Bottling Company – Ghana, and the Society of Women Against AIDS - Ghana. These groups have varying foci including children, development, equity, self-reliance, policy development and program implementation, public health and epidemiology, medical research, and socio-economic disadvantage. Rights are referenced with relative prominence among three

of these groups⁴¹⁰ but do not appear dominant in any case. Gender (5 donors) and development (4 donors) are the most frequent areas of focus. Respondents added that through the revolving fund “we are also helping ourselves”⁴¹¹ by giving soft loans to members.

At least in recent times there is evidence of donors being sought whose mandate resonates with specific projects, with one respondent speaking of how members come to her with a project idea and she subsequently searches for a suitable donor. One respondent commented that donors favoured a gender perspective, adding that donors liked the WUAAG was “all women.”⁴¹² Several respondents also explained that WUAAG had a reputation for transparency and openness which had enabled it to retain funding even while some funders had expressed wariness of funding groups of people living with HIV/AIDS due to past experiences with corruption. The group expressed some frustration with the fickleness of donors who pulled out, or would only fund essential services for part of the year.

6.2.4 Impact

“pleading for the government to give us drugs so that some of us can survive”⁴¹³

Respondents described the use of a variety of frames or messages in their advocacy. While these were described as being chosen based on the topic at hand, they did not appear to be selected in connection with expectations or experience of impact. Rather, respondents saw particular issues as being inherently or factually connected to specific messages. For example, one respondent felt that rights language could only be legitimately employed for claims with a clear basis in law, therefore, the correlation between laws and claims determined whether that language could be

⁴¹⁰AWDF, Global Fund for Women, Pro Link

⁴¹¹Author’s interview, Employee 1, WUAAG, 10 February 2010, Accra, Ghana.

⁴¹²Author’s interview, Lydia Asante, WUAAG, 19 February 2010, Accra, Ghana.

⁴¹³Author’s interview, Employee 1, WUAAG, 10 February 2010, Accra, Ghana.

used.⁴¹⁴ Other campaigns and approaches were explained based on need, calling attention to vulnerabilities.

Although organisationally peripheral, rights were frequently mentioned by one respondent, and occasionally by other respondents when probed. Within the organisation rights were mainly described as linked to specific activities and workshops where external experts were brought in to educate the women and to “train them on the rights that they have and how they can enforce them.”⁴¹⁵ One respondent explained that rights language was important because members were “entitled to enjoy [them]” and that these rights were “theirs for the taking.”⁴¹⁶ It was emphasised, however, that rights needed to be presented in a way that was “not abstract” but “very practical” and with direct relevance to lives of WUAAG members.⁴¹⁷

Several respondents described an organisational shift over time, with less emphasis being paid to outward-oriented advocacy, and more emphasis placed on inward-oriented education and advocacy aimed at their membership. Reasons for this change included a decrease in stigma as well as a shift in internal attitudes, with one respondent remarking that these days, “the women don’t care” as much about what others think of them.⁴¹⁸ Despite this decrease, respondents cited occasional rights messaging directed at the general public, usually with a simple message ‘to respect the rights of people living with HIV.’ Rights were strongly associated with law, and were understood as entitlements, with one respondent stating “we are advocating for their rights we

⁴¹⁴ Author’s interview, Lydia Asante, WUAAG, 19 February 2010, Accra, Ghana.

⁴¹⁵ Author’s interview, Lydia Asante, WUAAG, 19 February 2010, Accra, Ghana.

⁴¹⁶ Author’s interview, Lydia Asante, WUAAG, 19 February 2010, Accra, Ghana.

⁴¹⁷ Author’s interview, Lydia Asante, WUAAG, 19 February 2010, Accra, Ghana.

⁴¹⁸ Author’s interview, Lydia Asante, WUAAG, 19 February 2010, Accra, Ghana.

are not advocating for a special favour, no.⁴¹⁹ Another respondent when asked if the group used rights messaging for outward-oriented campaigns answered:

not really, we talk about it, the human rights is there alright, we know that the basic rights are there – [but] we don't really show them to the public.’’⁴²⁰

Within all responses there was a very narrow and specific understanding of rights with rights often viewed as the legal structures and mechanisms that existed to enforce them. Rights were sometimes understood as referring to the Commission for Human Rights and Administrative Justice (CHRAJ), sometimes as maintaining confidentiality of membership and, frequently as legal recourse. The process of choosing an advocacy frame was not understood as flexible or discretionary. Specific topics or campaigns were conceived of as directly linked to specific frames or arguments. Consequently, respondents reported that particular topics called for specific frames, WUAAG did not choose frames and apply them.

6.2.4.1 Campaigns

Respondents described two components of a campaign with a common theme: access to anti-retroviral medication.⁴²¹ One campaign involved a lack of access to medication at clinics, where medication appeared to be running out. A second current campaign involved the introduction of a new national insurance programme and the fact that anti-retrovirals were not completely covered by this program, instead being subsidised and costing five Ghana *cedis* per person per month.

⁴¹⁹ Author's interview, Lydia Asante, WUAAG, 19 February 2010, Accra, Ghana.

⁴²⁰ Author's interview, Employee 2, WUAAG, 10 February 2010, Accra, Ghana.

⁴²¹ Various referred to as anti-retrovirals (ARVs) or anti-retroviral therapy (ART)

6.2.4.1.1 Availability of Anti-Retroviral Drug in Clinics

Two respondents referred to an earlier campaign where WUAAG members found that anti-retroviral drugs were often unavailable and were told that “their ART [anti-retroviral therapy] was more or less running out at the clinic.”⁴²² Responding to this, the group held a demonstration “pleading for the government to give us drugs so that some of us can survive”⁴²³ and walking across town to the Ministry of Health to present their concerns. Respondents framed this campaign as presenting a request, with the verbs “asking”⁴²⁴ and “pleading”⁴²⁵ used in lieu of more aggressive terms such as “demanding” which imply an obligation. The march was described as “asking for something to be done”⁴²⁶ with “all these people with HIV holding their placards asking for ART.”⁴²⁷ Recollections of messages depicted on placards called on themes of need, sympathy and compassion, examples offered included: “We need ART,” “Have you abandoned us?,” “Do you want us to die?” “We are also people and we deserve equal attention and equal opportunity with respect to health care” and “Don’t you care about us?”⁴²⁸ These messages called to a human obligation, not based in rights or law, but lying somewhere on the spectrum between empathy and pity. One respondent described them as “messages that are not pleasant and messages that tell the truth.”⁴²⁹

⁴²² Author’s interview, Lydia Asante, WUAAG, 19 February 2010, Accra, Ghana.

⁴²³ Author’s interview, Employee 1, WUAAG, 10 February 2010, Accra, Ghana.

⁴²⁴ Author’s interview, Lydia Asante, WUAAG, 19 February 2010, Accra, Ghana.

⁴²⁵ Author’s interview, Employee 1, WUAAG, 10 February 2010, Accra, Ghana.

⁴²⁶ Author’s interview, Lydia Asante, WUAAG, 19 February 2010, Accra, Ghana.

⁴²⁷ Author’s interview, Lydia Asante, WUAAG, 19 February 2010, Accra, Ghana.

⁴²⁸ Author’s interview, Lydia Asante, WUAAG, 19 February 2010, Accra, Ghana.

⁴²⁹ Author’s interview, Lydia Asante, WUAAG, 19 February 2010, Accra, Ghana.

Respondents felt that this campaign had been successful, commenting “it has worked,”⁴³⁰ noting that afterwards, “the medicine was coming.”⁴³¹ One respondent described the campaign stating, they go on a demonstration [and] the next time they go to the clinics their medicines are there.”⁴³² When asked why they felt this initiative had succeeded, one respondent highlighted the importance of visibility for a group of people often fearful of identifying themselves publically, noting, “if we are all sitting down saying we are not going to talk – the treatment will never come. So once some of us got up to come out and talk on it.”⁴³³ Another highlighted loss of face for politicians, stating: “when you go on a demonstration it is like you are washing their dirty linen in public and they have to shut you up.”⁴³⁴ She elaborated, “the only way they can shut you up is by giving you what you need; especially when it is a necessity.”⁴³⁵

6.2.4.1.2 Funding for Anti-Retroviral Drugs

All three respondents commented on current work to push the government to include anti-retroviral drugs to be in the basket of medications and services fully covered by the new national health insurance programme. The group described cooperation with the National Association of People Living with HIV/AIDS in Ghana (NAP+), and advocacy through the Ghana AIDS Commission. One respondent remarked that the impetus for the campaign came from a question from the membership who simply asked, “why can’t health insurance cover (ART)?”⁴³⁶ Two main strands of argumentation were put forward by respondents. First, there was a clear need for

⁴³⁰ Author’s interview, Lydia Asante, WUAAG, 19 February 2010, Accra, Ghana.

⁴³¹ Author’s interview, Employee 1, WUAAG, 10 February 2010, Accra, Ghana.

⁴³² Author’s interview, Lydia Asante, WUAAG, 19 February 2010, Accra, Ghana.

⁴³³ Author’s interview, Employee 1, WUAAG, 10 February 2010, Accra, Ghana.

⁴³⁴ Author’s interview, Lydia Asante, WUAAG, 19 February 2010, Accra, Ghana.

⁴³⁵ Author’s interview, Lydia Asante, WUAAG, 19 February 2010, Accra, Ghana.

⁴³⁶ Author’s interview, Lydia Asante, WUAAG, 19 February 2010, Accra, Ghana.

ARVs and a lack of other forms of funding for those who needed the medication. The Ghana AIDS Commission, the only WUAAG donor which has consistently been providing funding for ARTs, had only been providing funding for six months of each year. WUAAG staff argued that the medication should be free because the “majority of membership are unemployed”⁴³⁷ and “people just stop taking [ARVs] when they don’t have money.”⁴³⁸ Highlighting the dire health consequences of poverty, one respondent stated simply, “the [government] shouldn’t bother so much about cost, it’s their lives.”⁴³⁹ The second line of argumentation emphasised equity between health conditions and value for money. Respondents argued that “it’s not right” that “women in labour get to deliver for free” and that anti-malarials and TB medication are fully covered while ARVs are not.⁴⁴⁰ Explaining that someone who is HIV positive “can go for six months without using [...] health insurance” one respondent argued that “it’s kind of a rip off” for people living with HIV to contribute to a health care system that they use infrequently, while having to pay extra for the medication that they use every day.⁴⁴¹

This campaign, to remove the 5 *cedi* monthly charge was described as “just asking”⁴⁴² through the Ghana AIDS Commission for parliament to consider it. It was not described as being a rights issue explicitly. While one respondent partially framed it within the right to health care, fully subsidised medication was not seen as a right. She commented on the one hand, “we would say it’s a rights-based campaign because it can be read into the law” with reference to the right to access healthcare, but elaborated that they:

⁴³⁷ Author’s interview, Employee 2, WUAAG, 10 February 2010, Accra, Ghana.

⁴³⁸ Author’s interview, Lydia Asante, WUAAG, 19 February 2010, Accra, Ghana.

⁴³⁹ Author’s interview, Employee 2, WUAAG, 10 February 2010, Accra, Ghana.

⁴⁴⁰ Author’s interview, Lydia Asante, WUAAG, 19 February 2010, Accra, Ghana.

⁴⁴¹ Author’s interview, Lydia Asante, WUAAG, 19 February 2010, Accra, Ghana.

⁴⁴² Author’s interview, Lydia Asante, WUAAG, 19 February 2010, Accra, Ghana.

don't call it a right because it's not theirs for the taking. Someone is bringing in the drugs, the person has subsidised them and is making them cheaper. It's just advocating that, on the basis of the fact that you are allowing certain people to benefit from this scheme, allow me to also benefit from this scheme with my ARVs. If TB patients get treated for free, if other sicknesses are covered by the health insurance why is it that ART that costs just five *cedi* is not? What as an advocate what we can do is argue that it's discriminatory but I don't think we have ever tried to advocate for it as a right”⁴⁴³

For this reason, she argued “you can't insist on it” as “if it's not in the law it's not a rights issue” and only “when it is passed as a law then it becomes a right – then you can demand.”⁴⁴⁴ Rights language was only seen as appropriate when such rights were enshrined in law, and only seen as effective where there was a mechanism for legal recourse even if, as above, such recourse was only invoked as a threat. The comparison between health conditions was another theme touched upon by one respondent, who highlighted the inequities in both provision of medical services and social treatment between differing health conditions such as malaria, tuberculosis and cancer. Although these arguments hinged on comparison they also had a thread of compassion, in the sense of: government looks at other people why not us?

6.2.5 Conclusions: WUAAG

WUAAG was formed in response to isolation and discrimination and, in response, its organisational ethos emphasises belonging and inclusion. From within the group cultivates strength through belonging, outwards trying to invoke care from others through slogans such as “do you want us to die?” that tug at heartstrings rather than obligations. Unless explicitly articulated in law, the group does not rely on a rights frame and instead calls to human decency, care or compassion or, inequity between different health conditions highlighting the differences in services and social interaction between those with malaria and those with HIV/AIDS.

⁴⁴³ Author's interview, Lydia Asante, WUAAG, 19 February 2010, Accra, Ghana.

⁴⁴⁴ Author's interview, Lydia Asante, WUAAG, 19 February 2010, Accra, Ghana.

Respondents did not cite negative associations with the rights frame but rather viewed rights as limited and precisely defined entitlements that applied to some issues and not others.

Reflecting on the hypotheses, WUAAG suggests several important findings. First, at the intra-organisational level this case indicates that perspectives on the scope of rights may have an important influence on the use of the rights frame. Like other groups in this category WUAAG also highlights the importance of personal experience within the organisation and the role that plays in shaping advocacy messaging. Structurally WUAAG is a small, centralised membership-based organisation with a strong leader. This set-up could potentially incubate a rights-based organisation, however, the leader is not a rights champion and rights are seen as a limited concept that are not necessarily widely accessible and understood. Like NAP+, this group made few unsolicited references to other organisations either domestically or internationally, being primarily shaped by their constituency and local context. WUAAG does not exist in a setting where rights language is prominent. The group, however, did have international exposure, particularly for the organisation's President. This suggests, as indicated in several organisations already examined, that exposure to rights, including rights-based organisational training in this case, is insufficient. With reference to donors, WUAAG had donors of diverse orientations, but had comparatively fewer with a rights orientation and none that considered rights their primary frame. Finally, with respect to impact this case demonstrates a significant departure from factors seen in the rights mixed and rights dominant cases. Recalling some themes seen in the NAP+ case, WUAAG sees impact as tied to need often as communicated through personal experience.

6.3 Kuru Family of Organisations' Health Programs

*"We want life"*⁴⁴⁵

Geographically isolated and operating in a sensitive context, the Kuru Family of Organisations' health program (Kuru) makes a deliberate choice to avoid controversial language and taboo subjects in order to carefully address health issues in underserved San indigenous communities in Botswana's Kalahari and Okavango regions. Addressing HIV through the older and more understood condition of tuberculosis (TB), the group focuses on a general and positive slogan, "we want life" in order to move away from messages discouraging specific forms of behaviour. In this context rights are both locally unfamiliar and domestically unproductive as their use is associated with earlier more confrontational activism.

As a case Kuru reflects few of the features that were hypothesised to result in rights choosing. Intra-organisational factors including the background and previous employment of personnel appear to play a role in frame use but are subordinate to external factors such as advocacy context. Organisational structure is decentralised but, unlike other rights limited groups, is not membership-based. Unlike NAP+, this case does not illustrate the prominence of rights in one part of the organisation but not another due to a decentralised structure. Extra-organisational factors including local context, advocacy norms and political sensitivities play an important role in how advocacy is framed. Government partnership is important in the roll-out of several key programs and, as such, the anticipated government response to advocacy frames in an important consideration. Like the other rights limited groups organisational identity is strongly linked to the constituency served, as is organisational niche. Perceptions of impact are related to the accessibility and local appropriateness of both methods and frames used.

⁴⁴⁵ Kuru Health Programme Slogan.

6.3.1 Frame

*“re mmogo [we are together]”*⁴⁴⁶

While on the international stage the San are the group within Botswana who, or on whose behalf human rights language has most widely been used,⁴⁴⁷ rights language is at best peripheral among Kuru’s Community Health program. Of 32 wall materials⁴⁴⁸ only one, not produced by Kuru, makes an overt reference to rights. No mention of rights is made in a booklet describing the organisation’s history (Kuru 2007), which instead emphasises development. Annual Reports do not make prominent mention of rights for the Kuru Family of Organisations as a whole, with the concept cited directly only in the 2007 Annual Report which states that “KFO Community Health aims to empower remote communities to understand their rights, duties and responsibilities as citizens towards leading healthy lives” (Kuru 2007, 24). A current pamphlet of the Letloa Trust, a member organisation of Kuru, contains a similar reference.⁴⁴⁹

The health program’s chief slogan is *“re batla botshelo”* (Setswana) which means “we want life.” This slogan highlights positive actions towards improved health, in response and opposition to dominant approaches focusing on negative messages (ie behaviour that should be avoided). Secondary slogans, *“re mmogo”* (Setswana, “we are together”) and *cooca bo* (Naro, “the way forward”) are also used. These slogans emphasise unity and collectivity, future actions and positive aspirations. They are also intentionally general, and can be applied to any number of health-related issues. As the group’s 2007 annual report states:

KFO’s [Kuru Family of Organisations] health philosophy focuses around acceptance of the diversity of people and the incorporation of positive living techniques, including

⁴⁴⁶Kuru Health Programme Slogan.

⁴⁴⁷Particularly Survival International’s activism around the forced relocation of San people outside of the Central Kalahari Game Reserve.

⁴⁴⁸Wall materials include posters and other materials displayed on office walls and doors (including t-shirts, banners, print-outs, stickers, posters) as observed in July 2010.

⁴⁴⁹Annual Reports from 2004 -2009 were analysed.

practical methods of immune system boosting mind-body-spirit regardless of status (Kuru 2007b, 24).

This description mirrored the approach apparent in internally-produced materials, which centred on the “*re batla botshelo*” message in English, Setswana and Naro languages. Among Kuru respondents comments relating to rights emerged virtually only when probed. Respondents emphasised health, poverty alleviation and development in their descriptions of dominant organisational frames and objectives, with one respondent highlighting youth with specific reference to HIV work. The “we want life” slogan featured prominently in interviews, as did words indicating positive suggestions and movement such as ‘encouragement,’ ‘improvement’ and ‘empowerment.’

6.3.2 Intra-Organisational Factors Affecting Frame Selection

Kuru was registered in 1986, and the health program, centred within the Letloa Trust⁴⁵⁰ had 18 employees in 2009, growing to more than 30 by 2011 after funding interruptions caused a significant scaling back of operations in 2010.⁴⁵¹ Letloa’s Community Health Communications Centre, which coordinates health programming, is based in D’Kar, one of the larger settlements of San indigenous people in Botswana’s western Kalahari. Although it is the sole civil society group working on HIV in these settlements, the community health project foregrounds TB, using this better understood condition as an entry point to HIV. Based in the district with the country’s highest TB prevalence, Kuru’s health program is involved in advocacy, education and the production of informational materials, as well as service provision in the forms of community-

⁴⁵⁰The Kuru Family of Organisations is composed of a number of trusts. The Community Health program currently involves personnel at Letloa Trust, as well as at two other members of the Kuru Family of Organisations: D’Kar Trust (Community TB Care providers, and a health coordinator), and Komku trust (a lay counsellor).

⁴⁵¹A total of nine employees of Kuru involved with the Community Health program were interviewed, in July 2010 and July 2011 in D’Kar, as well as three government officials who had regular interaction with the group (2 in Ghanzi, 1 in Gaborone).

administered TB treatment and HIV testing. The group operates throughout the country's Kalahari and Okavango regions in the west and north-west of the country with community TB officers in many of these communities.

The health program creates health education materials, convenes community workshops around health topics, implements community-based TB treatment in cooperation with the Ministry of Health and, conducts advocacy for “equitable access and availability of health services” (Kuru 2009, 12) including for the availability of translation services in government hospitals and clinics. The Community Health Communications Centre is also charged with creating health materials in local languages and in pictorial form, and adapting information from national campaigns to be locally relevant. The role of the Community Health Communications Centre was described as:

Work[ing] with KFO members to create appropriate and effective communication, mobilisation and advocacy, which will allow communities to understand their rights, duties and responsibilities for leading healthy lives, with a focus on HIV AIDS and TB (Letloa pamphlet, 1996).

At the time of interviews, the organisation was also preparing to roll-out a new HIV testing program out of their D'Kar office.

From the beginning Kuru has been an organisation shaped not by a distinct issue, but founded and developed around a specific group of peoples whose cultures and experience are drawn upon to shape the group's approach. Described as “gr[owing] from the culture of the people that started it and still own it today” (Kuru n.d.), the group aims in both language⁴⁵² and approach to

⁴⁵²The organisation is closely though unofficially affiliated with a Naro language project which has been developing a written form of the language dominant in D'Kar and area.

ground its work in and for the communities in which it operates. Registered as a community non-government organisation in 1986, Kuru has informal roots dating to 1960s, when San⁴⁵³ people gathered around the Kuru name, a word which means “to do, to create” in five San languages (Kuru 2007, 5). As the name suggests, the group was intended primarily as a capacity-building, development and poverty alleviation organisation. In line with its name, the group’s logo emphasises a positive journey and is described as representing the “mythological rain bird which is believed to carry blessings and to use its tail to illuminate one’s path” (Kuru n.d.).

Kuru began in D’Kar before spreading to other communities and regions. Although very locally-oriented, from the outset the organisation has had important international personnel, with Braam Le Roux, a South African man who came to D’Kar in connection with the Reformed Church, one of the organisational founders. As the organisation grew over time, it came to involve projects as varied as preschools, leadership training, income-generation projects including a game farm and art exhibitions, a dance festival, and international exchanges and networking during the UN decade for Indigenous people (beginning in 1991). The organisation has not been immune to controversy, with Braam Le Roux briefly declared a prohibited immigrant in 1993 in connection with indigenous activism (D’Kar Museum display). Over time, the organisation grew and diversified, eventually in 2001 becoming the Kuru Family of Organisations, a network of eight different groups. The group is described as the “largest as well as the oldest NGO in Botswana” (Kuru n.d.).

⁴⁵³The terminology in both cases is inherently problematic. The San are also known as Basarwa (variously translated as people from the south, people who don’t herd cattle, people who have nothing, people from the sticks) the dominant term within Botswana, but considered derogatory by many San, San which has colonial origins and also initially was considered derogatory, Bushmen which is the term used by Survival International which some consider sexist, and Khoi-San, Kua, Khwei. The term San is used here as that is the term used by Kuru.

6.3.2.1 Personnel and Perspectives within the Organisation

The health program has a mix of employees with different levels of experience and exposure to the rights frame as well as differing cultural backgrounds. The project co-ordinator, who has a strong influence on advocacy framing and is directly engaged with advocacy initiatives clearly has experience with the rights frame. An American who has been in Botswana roughly a decade, Laura Martindale, came to the country with some background in HIV education and subsequently worked with Ditshwanelo – The Botswana Centre for Human Rights, on the creation of an HIV and Human Rights Charter. She has also participated in training around human rights and HIV with the Botswana Network on Ethics, Law and HIV/AIDS (BONELA) once in her current position at Kuru. Other employees did not report previous work with rights-based organisations, some coming to Kuru with experience working in organisations with a Christian and youth focus respectively. Among Batswana⁴⁵⁴ employees there is a mix of San and non-San employees, with community TB officers generally San from the local communities, and office-based positions often locally-based non-San Batswana. The 2009 Annual Report remarked that year as “particularly noteworthy year as it marked the first time in the history of the Kuru Family of Organisations that we have the most senior positions in the Organisation being occupied by citizens” (Kuru 2009, 5).

When describing their work and the purpose of their organisation, access to information and services were heavily emphasised in interviews with Kuru employees. Immersed in a situation of relative deprivation and with very little material in local languages, the group makes strong efforts to locate local contexts and language through which to deliver its health messages. The

⁴⁵⁴Batswana is the plural word for citizens of Botswana.

current campaign centred around the phrase “*re batla botshelo*” originated from community consultation. A current project entitled *o a bua* (“do you hear?”) asks community TB officers to record conversations they encounter around health programs in order to effectively target community beliefs about transmission and health interventions. Beliefs that HIV originates from condoms, or education, or that it is not really any different from TB, with which the community is more familiar, continue to exist. As such, the group is tasked with communicating basic health information as well as advocacy messages around access and health interventions.

While Kuru does not overtly define the struggles of its community as rights, it does explicitly understand these health challenges to be group and identity based. Most respondents referred to collective disadvantage, with comments such as “the San are still behind,”⁴⁵⁵ and noting difficulties in accessing services, language barriers and discrimination. Additionally, in interviews, respondents referred to comments made by non-San local leaders where they referred to “*Basarwa*” as being the ones with TB, linking health condition and group status, and linking group and health status to excessive drinking, smoking, or poor hygiene. While there has been recent national and international attention on “Most At Risk Populations,” with reference to HIV, the San community is not understood by the national government to be part of this category. One respondent expressed frustration with this, asking:

When are you [government] going to realise that your primary prevention efforts are not reaching some of the most at risk populations? ... You are trying to tell me that your most at risk populations are sex workers in Francistown,⁴⁵⁶ I’ll give you another most at risk population, because there’s an old lady here... she’ll come and tell you *kana* I’m a midwife... We used to hoard gloves in the house [because there were none at the clinic]
.....

⁴⁵⁵ Author’s interview, Employee 2, Kuru Family of Organisations, 8 July 2010, D’Kar, Botswana.

⁴⁵⁶ The country’s second largest city.

Even their access to participation is so extremely very limited, we talk of access and we talk of language, it's not seen maybe as so serious as sex work. Maybe because their challenges are maybe quite different than the majority, they just get brushed under the carpet? Is it because we are not having our voice that is together with our isolated populations?⁴⁵⁷

Despite these clear frustrations, rights emerged in interviews virtually only when probed and were viewed by some as being an outside concept with limited understanding within the community. Respondents often spoke about capacity building of the communities that they work with, in some cases seeing an unrealised rights dimension to this scenario, linked to education and empowerment. When prompted regarding human rights respondents often spoke about the right to access health care services, at all and, on par with other Batswana.

we wanted the Sans to be equal with those people at Mahalapye and Francistown, to go, these people are getting their services at the clinic, and our people they are not getting their services *daily* as people at Mahalapye, people at Mahalapye maybe they understand these issues and our people they are just there ignoring it, just knowing that these health issues are for other people....If they know their rights, they can talk about their problems ... they can pull up their socks and go and complain further.⁴⁵⁸

Respondents recalled frustrations both in encouraging their community to access services, and in persuading the clinic, and other government services to be provided in relevant and accessible ways. Language and access were prominent features of responses, with a high level of aggravation with the lack of language-appropriate services. Respondents, as quoted above, expressed a dual frustration with reference to rights, both in terms of their lack of enjoyment and the lack of action of the part of community members to be empowered to claim them.

⁴⁵⁷ Author's interview, Laura Martindale, Kuru Family of Organisations, 9 July 2010, D'Kar, Botswana.

⁴⁵⁸ Author's interview, Employee 2, Kuru Family of Organisations, 8 July 2010, D'Kar, Botswana.

6.3.3 Extra-Organisational Factors Affecting Frame Selection

6.3.3.1 Domestic Factors

The advocacy frame employed by Kuru is heavily influenced by the perception and politics surrounding the group of people with whom they work. The 40,000 San constitute about 3% of the Botswana population (Good 2008, 103), living primarily below the poverty line, and having high levels of infant mortality, and low rates of literacy and education (Hitchcocks 2002, 797-798, Good 1999). Inhabiting the periphery of the country, the San seldom feature in national discourse and, when they do are often addressed simply as ‘Remote Area Dwellers’ (Saugestad 2001, 124-125). References that do arise tend to emphasise the need for modernisation and integration. As Mazonde states, “[w]hile Botswana is clearly moving towards accommodating the various cultures of its different peoples, its policy towards the San is different and seeks to integrate them into the culture(s) of mainstream Batswana” (Mazonde 2004, see also Taylor 2004).

Tensions around the San and land use, and particularly around related activism, have had an important influence on the way Kuru conducts advocacy. In 1986 the government began advocating that the mostly San residents of the Central Kalahari Game Reserve (CKGR) should leave the reserve (Hitchcock 2002, 806), with the first of three large-scale removals⁴⁵⁹ and relocations in 1997⁴⁶⁰ (Survival International).⁴⁶¹ International indigenous advocacy group Survival International (SI) was heavily involved, invoking allegations that the relocations were

⁴⁵⁹To be followed by another set of removals in 2002 and 2005.

⁴⁶⁰Created in 1961 by the British colonial administration the CKGR was intended to be both a nature reserve and as a way of “protecting the rights of the 5,000 or so people (mostly San) living within its 52,347 square kilometre area who wanted to maintain hunting and gathering as part of their lifestyle” (Michael Taylor 2004, 151).

⁴⁶¹The CKGR has no surface water.

connected to diamond exploration (see Survival International, see also Good 2008).⁴⁶² A decision was reached in 2006, with the court ruling that the relocations had been “unlawful and unconstitutional,” but that the government was not obligated to provide services in the CKGR (Survival International website). Despite this decision, tensions and conflicts are ongoing (Survival International website).

Related primarily to this series of events, the San have been the subject of widespread rights-based mobilisation and advocacy. Of any clearly identified group in Botswana they have the most vocal, and the most consistently rights-based campaigns on their behalf. At the local level, mainstream human rights organisation Ditshwanelo – the Botswana Centre for Human Rights (Ditshwanelo) considers ethnic minority rights to be one of their primary areas of work (Ditshwanelo website). The San organisation, First People of the Kalahari⁴⁶³ (FPK), has also campaigned vocally on San rights sometimes in collaboration with SI. Some local groups, however, have found SI’s approach off-putting. Kuru’s late leader Braam le Roux stated “I think there’s a general fear amongst NGOs and everyone out here about Survival” and Ditshwanelo director Alice Mogwe noting that their “confrontational tactics” were generally not a strategy to which governments in the region responded positively (Good 2008, 138). SI’s activism around the CKGR removals, in particular, was intensely controversial within Botswana, with petitions from overseas gaining front-page newspaper coverage.

Situated within this context, and requiring active cooperation and partnership with government in order to implement some of their programs, Kuru has avoided rights language and

⁴⁶² Although no official reasons were given Kenneth Good, at the time a Professor of Political Science at the University of Botswana wrote about the San and about the connection to Diamonds and was declared a prohibited immigrant and deported in 2005.

⁴⁶³ Also known as Kgeikani Kweni.

confrontational framings. Domestically isolated from the Gaborone-centred national NGO community Kuru is one of very few non-governmental organisations working in the Kalahari region of the country, and is often the sole NGO engaged with the communities in which it works. In order to carry out key areas of work the group requires cooperation with government. In the case of the community TB care program the Ministry of Health works as an active partner that could, and has suspended activities with a government change of heart.

While a rights approach could be understood to shed light on this group, concerns about the backlash related to SI and linguistic connections to more controversial topics may be a key reason for caution around rights language. One respondent commented that the language used depended on the audience, noting:

you have to adapt it to who you're talking to, and even the government at the district level you have to sort of pad it, in a way, so that they will actually listen to you. You talk of different language groups and not necessarily that this is an issue of rights ...⁴⁶⁴

The approach that it seen as useful in the organisation's regular dealings with government is one of dialogue focusing on specific practical elements including language and the need for translation, and the availability of medication and health care services.

With regard to advocacy oriented towards the communities with whom they work, respondents viewed human rights language not as objectionable or controversial, but as unfamiliar. Kuru interviewees did not see human rights as having obvious local cultural grounding. In fact, the term human rights does not even have a local equivalent in Naro, the community's dominant language. Instead, *ditshwanelo*, the Setswana term, was favoured. When pressed, one respondent

⁴⁶⁴ Author's interview, Laura Martindale, Kuru Family of Organisations, 9 July 2010, D'Kar, Botswana.

asserted that the closest concept they had in Naro was *gozi quncom*⁴⁶⁵ which means “how things are being done,” commenting that human rights “originate from somewhere not from us.”⁴⁶⁶ One respondent explained that human rights awareness that had come through outside connections had had limited impact on the community, touching individuals rather than the settlement as a whole. In contrast, Kuru’s slogans, in particular “*re batla botshelo*” were widely known in the community and associated with the organisation’s health work.

6.3.3.2 International Influences

Although isolated in many respects, Kuru does have a long history of international connection, primarily in the form of personnel. Kuru has had significant leadership from Braam Le Roux, who held various leadership positions from the organisation’s birth until 2007. The group has had a number of international staff and volunteers over the years on both short and long term contracts through groups such as World University Service of Canada (WUSC), the US Peace Corps and Skillshare International. At the time of interviews in July 2010 the group had a WUSC volunteer, and in June 2011 a Dutch Skillshare volunteer. Since 2005 the community health program coordinator has been an American woman, long resident in Botswana. These volunteers and employees tend to carry out key organisational functions as the group has difficulty finding individuals with specific educational qualifications and experience locally. Beyond the community health program, at the level of Kuru leadership, the Executive Director Kaelo Mokomo sat on the board of directors of WUSC.

⁴⁶⁵This is my estimation of spelling, with the ‘g’ aspirated and the ‘q’ and ‘c’ indicating different click sounds. Naro is in the process of becoming a written language but spelling of words is still inconsistent and contested. Consultation with native speakers in the field has not resulted in confirmed spelling.

⁴⁶⁶Author’s interview, Employee 4, Kuru Family of Organisations, 9 July 2010, D’Kar, Botswana.

Apart from personnel the health program has limited international interaction, little participation in international conferences and irregular communication with international groups. In contrast with all other groups studied, for example, no Kuru respondents had participated in any of the World AIDS Conferences. Two employees did, however, travel to the South African National AIDS Conference in July 2011. Those at Kuru described a situation of relative isolation, with suboptimal internet access and limited contact with groups outside of the country. One Kuru respondent described an exchange program which brought Canadian and American indigenous peoples' groups to Botswana, amongst whom an indigenous rights perspective is gaining prominence. She remarked that the differences between the San and North American indigenous people with respect to education, advancements and self-determination were so striking that it was difficult to find common ground. Despite these sporadic interactions, however, a key aspect of the health program's main message was influenced by an international actor. While the *re batla botshelo* slogan was developed at a grassroots level, it is linked to a positive health approach, developed in part through training with a South African group called Empowerment Concepts. This approach has become the group's dominant frame of understanding and communications health messages and interventions.

While the group is not connected with international activities, events or organisations on a day to day basis, a small but key component of international staff have meant that the organisation is linked to current international ideas around approaches, frames and development assistance. The group, at least at the level of coordinators and higher leadership, is well aware of rights approaches. Therefore, the decision not to use the rights frame is actually a decision, rather than the result of limited awareness or understanding. The group has drawn on specific international

resources, specifically Empowerment Concepts in order to craft an approach that resonates and is accessible to the community with which they interact, while drawing on government documents and objectives in order to dialogue productively with government departments which may have specific sensitivities and aversions to the rights discourse in relation to the San.

6.3.3.3 Donors

Kuru's experience does not illustrate clear funding imperatives which have dictated advocacy approaches. Like many Botswana NGOs, Kuru's health program receives the bulk of its funding from donors located outside of the country. The program is currently funded through the Swedish International Development Cooperation Agency, an organisation with a strong inclination towards rights-based approaches. Kuru also partners with the Botswana Ministry of Health in its community TB care program, which is less rights-oriented. Respondents did not describe donors as being predisposed to the positive health approach employed by Kuru, nor did they indicate any donor pressure either towards or away from the rights frame. Respondents felt that donors were generally positively inclined towards funding advocacy.

6.3.4 Impact

Impact and accessibility are key concepts for Kuru in the selection of messages and particularly in its ongoing "*re batla botshelo*" campaign, which was developed and shaped around the needs, culture and comfort of the San people. Arising from community consultation, the slogan dominates local education, advocacy and programming, while messages of public health and access are emphasised when dealing with government agencies. The community-oriented slogan

draws on a communal identification ('we') linking to a more collective understanding of health and healing⁴⁶⁷ and calls for a simple and positive association with health. "We want life" emphasises a holistic, non-disease-specific approach to health and well-being (mental, physical, emotional, spiritual) and highlights and promotes health-seeking behaviour. One employee described the goal of the approach as to:

strengthen immunity with a positive mind, I mean it involves mind, body and spirit, and the effects of motivation rather than a fear understanding of health....It's like okay if I drink this orange juice it's going to be good for me, rather than, oh god if I don't then I'll be sick. You know, the whole concept of positivity and wanting to improve your life, wanting to make a change, allows you to see opportunities in order to do that.... [Unlike] in public health when we want people to fear, like if you take this, it's going to kill you but then you're not going to want to, but it also shuts you off it's like that negativity doesn't allow you to see an alternative or an opportunity for improvements.⁴⁶⁸

While the community health program works on many issues including HIV and maternal child health, the program's current primary focus is on tuberculosis. HIV is a relative newcomer to the community, having entered surrounded by myths (ranging from the virus having been brought in by the white man, to condoms bringing infection, etc.). TB, on the other hand has been in the community for a long time and is very familiar to the population. As one respondent described it "TB is like our blanket,"⁴⁶⁹ it is something familiar that every family has had, and that everyone has seen someone die from. Respondents referred to both saturation about HIV, resulting in resistance, and to a general lack of knowledge about the disease and an unwillingness to test.

Despite the insistence by several respondents that HIV was not difficult to talk about, it was clear from both responses and activities, that it was not in practice talked about with the same freedom and frequency as TB. TB was described as both a goal (as the area has some of the highest TB

⁴⁶⁷Traditional healing for example was described as often entailing healing dances involving the whole community.

⁴⁶⁸Author's interview, Laura Martindale, Kuru Family of Organisations, 9 July 2010, D'Kar, Botswana.

⁴⁶⁹Author's interview, Employee 3, Kuru Family of Organisations, 8 July 2010, D'Kar, Botswana.

rates in the country, including several cases of non-compliant multi-drug resistant TB), as well as an entry point. One respondent explained, “it allows us to open doors and talk of way more issues,” with TB “they are much more open, TB is not as controversial, it doesn’t involve sexuality, it doesn’t involve as much introspection.”⁴⁷⁰ In framing health as “we want life” and focusing on TB, the organisation is deliberately drawing away from the controversial and towards the familiar, collective messages and experiences of the community. Health is understood less as a right within this approach, and more of a desire, and one that is collective rather than individual. As one respondent described it, “for us to stay here long we have to be together, and stay together, and like our life.”⁴⁷¹ Responding to past interventions, and aiming to ground their approaches within the communities in which they work, Kuru addresses a vulnerable population by choosing local, non-threatening, positive and general messages around health. In doing so, the organisation aims to increase uptake of services and health-seeking behaviour among marginalised populations who may feel alienated from health services having had negative interactions, or no interactions at all with health services and outside agencies in the past. Threats and the foreignness of interventions have led Kuru to base their approach in comfort, familiarity and positivity.

Assessing the effectiveness of this campaign is very difficult because there have been significant disruptions in funding, cutting the number of community TB officers from more than thirty to three for roughly a year. There has also been variation in the level of government buy in and capacity, including a seven month gap, during which government revoked authorisation for

⁴⁷⁰ Author’s interview, Laura Martindale, Kuru Family of Organisations, 9 July 2010, D’Kar, Botswana.

⁴⁷¹ Author’s interview, Employee 2, Kuru Family of Organisations, 8 July 2010, D’Kar, Botswana.

community TB officers to administer directly-observed TB therapy. There have also been drug shortages and a health sector strike which significantly disrupted services. At a community-level, however, the slogan is well known and clearly identified with the program, demonstrating a successful campaign of awareness and outreach.

6.3.5 Conclusions: Kuru

The Kuru health program navigates complex waters in its health work and interaction with government. While those in government directly connected to Kuru's work recognise and appreciate their work, and acknowledge their expertise in working with San communities, on a larger scale the San community and its health issues remain peripheral. In this context, using rights in advocacy makes linguistic links to past campaigns by SI and their partners, which were understood locally as confrontational and unproductive. Although at the leadership level Kuru health personnel clearly have exposure to and knowledge of rights language, they choose not to use it. Instead, they rely on locally grounded concepts of positive health and use the more familiar TB as an entry point to the more controversial HIV.

Reflecting on the hypotheses, Kuru indicates the personal experiences of personnel in relation to rights are mediated by the organisation's external environment. The group makes a strong and deliberate effort to ground its campaigns in the languages and conventions of the San people with whom it works, and endeavours to maintain a productive and cooperative relationship with government. Government partnership is important in the roll-out of several key programs and, as such, the anticipated government response to advocacy frames is an important consideration. These two factors have a strong influence on the group's advocacy method and messaging, pulling the group towards the local over the international, and towards positive and cooperative messages over ones that are negative or confrontational. The group has some level of

international connection, but is generally less connected internationally and less domestically connected than other groups examined in this study and has little interaction with rights-based organisations. Government partnership is important in the roll-out of several key programs and, as such, the anticipated government response to advocacy frames is an important consideration. As with other groups in this category, Kuru's organisational identity is tightly tied to the constituency it serves. However, unlike the other two organisations, Kuru does not serve a support function and is largely staffed by people outside of this group. While organisational niche is also strongly linked to the constituency Kuru serves, in a more isolated NGO environment differentiation from other groups is less important than in urban centres. Finally, expectations and experiences of impact are related to the accessibility and local appropriateness of advocacy framing and methods.

6.4 Rights Limited: Conclusions

The three organisations examined in this chapter illustrate several differing logics with relation to the marginal or non-use of rights in their advocacy including both active avoidance and passive non-use. At one end of the spectrum, Kuru's health programmes operate with knowledge of a rights approach but personnel choose to emphasise issues of health access in dealings with government, as rights language is particularly sensitive with reference to the San indigenous group with whom they work. In community-based advocacy, rights do not appear to have negative associations but are considered outside concepts that are less accessible than the "we want life" positive health approach that the organisation has endorsed. Women United Against AIDS Ghana (WUAAG) exists with a specific and limited understanding of rights. The group does not deliberately avoid rights as a strategy but views it as concrete rather than conceptual and applying only to legally specified issues. Instead the group emphasises personal messages

highlighting need and calling to the humanity of political actors. Like WUAAG, many NAP+ respondents saw rights as specific and limited concepts, often viewed as synonyms for enforcement bodies within the Ghanaian legal system. Although a minority of respondents saw rights as a component of their organisation's approach, most respondents described stigma as the overlying frame within which NAP+ understood and carried out its work. The personal element was important for both WUAAG and NAP+, with the latter emphasising personal experiences through testimony.

Within several groups there was a notable split in exposure to human rights language as well as in the understanding of how and whether it applied to an organisation's advocacy, depending on where respondents were positioned within organisations. In both Kuru and NAP+, those in higher level, more policy-oriented positions were more likely to reflect a deeper articulated understanding of rights, though this increased understanding did not lead to a shared view of their utility. All groups received significant international funding, though each of the three also received some funding from their respective domestic governments. In each case donors had a variety of favoured approaches and each organisation had some donors that employed the rights frame, with WUAAG the lone case with no donors that employed rights as their dominant frame. Kuru, the case with the lowest use of rights, is primarily funded by SIDA, which has a strong rights orientation and which also funds groups in the rights dominant category. There did not appear to be a donor pull away from rights language, and reasons for its non-selection by the groups examined here appeared primarily influenced by local relevance and accessibility of language. Although each group had some level of international connection, in most cases it was relatively limited beyond the level of leadership or, in NAP+'s case beyond the headquarters.

The approach employed by NAP+ and WUAAG provides an interesting contrast to the groups in the chapter examining organisations with a dominant rights frame. While these two groups utilise stories of hardship to connect with others, emphasising need, pain and vulnerability, rights-oriented groups usually highlight strength and entitlement. Although these two approaches, appealing to very different human emotions and relying on different portrayals, appear opposite, both call to a similar discourse. Both approaches aim to emphasise commonality and shared humanity. Although existing in different contexts, Ghanaian practices of testimony which call out to people's emotions are not entirely different from BONELA's *botho*-based human rights arguments, which speak to shared humanness, illustrating and reinforcing our own humanity by how we treat others. These approaches, however, do reflect different understandings of power relations when it comes to campaigns directed at government. In rights-based advocacy, particularly as illustrated by TAC, but also apparent in work by ARASA and to a slightly lesser extent BONELA, rights-based arguments are understood as claims which are rightfully owed to the recipient. These claims, as such, are not being requested, but are entitlements that must be fulfilled. WUAAG's description of their campaigns for access to ARVs stand in marked contrast, as members pleaded and asked for medication calling to human decency but not to law or rights owed to them as either people or as citizens. In Kuru's situation, where arguments could very easily be couched in rights discourse, basic access to services is still an issue on both sides, with the group aiming to inform the communities in which they work that services exist for them and how to access them, all the while negotiating with government to improve service provision. In this context, the group chooses to emphasise an 'encouraging' strategy focusing on a generalised positive health message.

With the exception of Kuru, groups examined in this chapter did not make a deliberate choice not to refer to rights. Instead, human rights language did not leap out as relevant, local and logical for these organisations, often being understood as a limited and specific concept that could only be used in distinct circumstances. In each of these settings, rights was not an easily understood and familiar concept at the grassroots level of the groups. It did not readily translate into practical steps, nor relate directly to concepts of empowerment. In contrast with groups in the rights dominant group, organisations in this category were far more likely to hold a constituency-based organisational identity. In two of three cases organisations were membership-based (NAP+ and WUAAG) and in two cases (NAP+ and Kuru) groups had decentralised structures. In contexts where rights as not dominant locally, these organisational factors could inhibit the spread of rights discourse where it does exist to some extent at a headquarters level (as is the case with NAP+). In all cases groups were far more likely to be influenced by personal experiences and to primarily identify with representing a group of people rather than an issue. This focus could entail greater frame variation or flexibility as campaigns are shaped around a population rather than an organisational frame.

Chapter 7: Comparing Across Categories, Themes and Countries

The previous three chapters have conducted a detailed examination of the factors that led groups to employ rights in their HIV advocacy, either as a dominant frame, amid other frames, or in a limited manner. Drawing on the findings from these three groupings, this chapter seeks to compare cases in three directions. Part 7.1 is dedicated to comparison between these three categories with respect to intra-organisational and extra-organisational factors affecting frame selection, and with regard to relationships between frame and impact. Part 7.2 examines emerging themes from the cases, using these as mechanisms of comparison. Part 7.3 takes a geographic comparison approach, grouping cases by location. Finally, these three types of comparison are linked with the aim of drawing conclusions.

The comparative analysis of these nine cases, while revealing tendencies rather than firm laws, demonstrates that people and personalities are at the centre of the adoption, adaptation, sustenance and spread of rights language. The role of leaders, in particular rights champions, is chiefly important in the organisational choice to adopt and employ rights language over time. This leadership is constrained or facilitated by structural factors at the organisational level, with secretariat-based structures more conducive than membership-based structures to the development of rights-based organisational culture in contexts where the discourse is not prominent. At the individual level, belief in the concept of human rights and in its impact on individual agency is central. Finally, the setting of the organisation, both in terms of geography and with respect to the civil society sector, is a critical influence on frame selection and organisational identification.

The factors outlined above appear to come together in two configurations which result in a rights dominant organisation. First, in the absence of a popular discourse on rights a leader with a strong belief in rights can, in a small secretariat-based organisation gradually build and develop an organisational culture of rights and occupy the rights niche within the NGO sector. Over time this rights orientation becomes self-reinforcing, drawing in others with a similar commitment to rights. Second, in the presence of a strong popular rights discourse, such as South Africa, a rights oriented leader is better able to manage a more disparate membership-based structure because this frame is already a common language and can benefit from other societal supports.

In contrast, groups who make selective, limited or no use of rights illustrate a different series of trends. Among these groups, personal experiences and membership or constituency play a more critical role in shaping advocacy frames, often reinforced by an organisational structure which is membership-based. Organisational identity and niche are more often tied to constituency or to a particular process of advocacy. Rights mixed groups usually encounter rights language through interaction with other groups and individuals, often, but not always located outside of the country. These interactions tend to be erratic and topic-based, influencing some individuals and campaigns, but not the overall organisational perspective. Rights limited groups often view rights as specific, limited and legal constructs rather than expansive concepts, understanding them as abstract and, at times remote, from the groups with whom they work.

7.1 Comparison Across Categories of Cases

Mirroring the structure of the case studies, this section compares within and across categories of cases (rights dominant, rights mixed and rights limited), with respect to three areas affecting frame selection: (1) intra-organisational factors, (2) extra-organisational factors and, (3)

perceptions of impact. Despite the uniqueness of each case, this comparison illustrates a number of key distinctions in each of these three areas. Initial mandate and leadership are key frame determinants among rights dominant groups, while personal experience is a more critical factor in frame selection among rights mixed and rights limited groups. Rights dominant groups tend to occupy an organisational niche defined by frame or technique,⁴⁷² while groups in the other two categories often hold a constituency-based niche. With respect to impact, rights dominant groups consider rights a strong catalyst for change, while utilising an appropriate process⁴⁷³ is critical for most rights mixed groups and sharing personal stories of need and vulnerability is pivotal for rights limited groups. The variations described above suggest that groups place differing emphasis on the various components of advocacy, with some emphasising the ‘what’ (message or frame), some highlighting the ‘how’ (process) and others placing primary emphasis on the ‘who’ (constituency or voice).

7.1.1 Intra-Organisational Factors Affecting Frame Selection

Among the three groups (BONELA, ARASA, TAC), with a rights-dominant approach, founding personnel and circumstances played a critical role in the selection and maintenance of the rights frame. Groups were explicitly established as rights-based and with a mandate of contributing a rights-based approach to HIV interventions. In two of three cases (ARASA, TAC) founding directors were involved in the set-up of the organisation. In BONELA’s case the rights orientation was included in the UN Project Support Document that detailed the establishment of a network on ethics, law and HIV which preceded the hiring of the group’s first director. With

⁴⁷²Techniques include mass mobilisation and legal action.

⁴⁷³Process here refers to how advocacy is conducted, for example, whether advocacy includes broad consultation, whether it is community-based and consultative, whether it involves dialogue. In contrast with frame, process focuses on the nuts and bolts, the methods of advocacy as opposed to the content or language of advocacy.

ARASA, a collection of Southern African rights activists working on HIV met at a rights-based UN meeting in Geneva and decided there needed to be a formalised regional association of groups working on HIV and human rights. While this initial conversation occurred outside of the region, the origin of rights was Southern African as all founders were from the region and formed an association based on their common perspective. With TAC, the death rate of HIV was the direct impetus for the group's formation, but its founder, activist Zackie Achmat brought his own human rights orientation, also launching the group at a time (Human Rights Day) and location that called to South Africa's rights-based anti-apartheid struggle. In all three cases, founders, or founding directors had a clear rights orientation, with the two founding directors interviewed noting the impact of their leadership in similar ways, commenting "it was very much dependent on the leadership"⁴⁷⁴ and "it's what I've always done."⁴⁷⁵

In each of these three cases leadership consisted of 'true believers.' These leaders are individuals with a strong personal belief in rights who adopt this frame based on this belief rather than an expectation of strategic impact or donor popularity. As ARASA's director noted in reference to her organisation's use of rights:

Maybe we're completely wrong. Maybe human rights don't work in the context of HIV. [laughs] It's not so much evidence-based advocacy as advocacy based on principle.⁴⁷⁶

Yet, in the absence of evidence (in some cases), frequently without domestic support for the rights discourse, and in each case in the face of fluctuating donor interest in the rights frame, leaders in these three organisations continued to emphasise rights. This finding is surprising, not

⁴⁷⁴ Author's interview, Christine Stegling, Former Director, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 24 January 2011, Brighton, United Kingdom.

⁴⁷⁵ Author's interview, Michaela Clayton, AIDS and Rights Alliance for Southern Africa (ARASA), 29 July 2010, Windhoek, Namibia.

⁴⁷⁶ Author's interview, Michaela Clayton, AIDS and Rights Alliance for Southern Africa (ARASA), 29 July 2010, Windhoek, Namibia.

in the sense that those who strongly believe in rights would continue to do so even when it places them outside of dominant discourse, but in the sense that even in such situations rights-based leadership would be able to maintain such an orientation at an organisational level and not be crowded out by other influential factors. While I would not expect individuals with no belief in rights to employ it emphatically, or for those who hold a strong belief in rights to abandon it when it waned in popularity, it would not be unreasonable to expect to see a ‘playing up’ or ‘playing down’ of rights in line with these external factors.

Instead, rights-oriented leadership served to recruit and sustain a rights-based organisational culture even in contexts of isolation and in unpopular times. The three rights dominant cases suggest that leadership created a reinforcing culture of human rights within the organisation, which, in the cases of BONELA and TAC, persisted even after the departure of the founding director. Interestingly, in all three cases other respondents did not cite leadership or organisational history as the reason for their reliance on rights. Instead, these respondents reflected on their own personal belief in the topic, highlighted the participatory benefits of a rights-based approach, and emphasised that rights are referenced because of the existence of violations. This suggests that these respondents were either recruited as individuals who already strongly believed in rights or, that they were socialised into this belief through their interaction with the organisation.

Groups in the mixed category (NACWOLA, SAfAIDS, TASO) were, in two cases, strongly influenced by individual experiences of living with the virus and the consequent stigma. In NACWOLA’s case the organisation’s identity as a group founded by HIV positive women for HIV positive women continues to be the most important factor in the manner in which the group

conducts advocacy. Within this context, several respondents reported a shift over time towards a greater emphasis on rights, though still linked strongly to gender. Sources of exposure to rights included staff experience, working in coalitions on advocacy campaigns with rights-based groups, and interaction with international personnel who held that orientation. In the case of TASO, the oldest organisation studied, early experiences of stigma and lack of access to care prompted an emphasis on the idea of ‘living positively’ which was sometimes articulated in conjunction with ‘equal rights.’ SAfAIDS, the one organisation of the three in this category that is not membership-based, identified primarily with process rather than frame, although it did note development and human rights as key approaches. This group placed the greatest emphasis on the production of information and on dialogue as a process of capacity building on issues relating to HIV. Each of these groups was aware of and had contact with a human rights approach, but referenced it amid many other approaches. In two cases there was a temporal dimension. In the case of TASO, those who had been with the organisation longer were far more likely than newer employees to view rights as important. Conversely, at NACWOLA, human rights were described as “a new thing.”⁴⁷⁷

Among groups who made limited use of rights (NAP+, WUAAG, Kuru), themes of union and collectivity were prominent. Slogans and comments such as “coming together” (NAP+), “united we stand” (WUAAG), and “*re mmogo*” (we are together, Kuru) featured in the organisational understanding and experience. In the first two cases, personal experiences, frequently of stigma, rejection and isolation played an important role in shaping the approach of the organisation. In all three cases the group’s orientation and frame was primarily shaped by its constituency.

⁴⁷⁷ Author’s interview, Kintu E. Ivan, National Community of Women Living with HIV/AIDS (NACWOLA), 4 March 2010, Kampala, Uganda.

NAP+'s frame is shaped by its membership of people living with HIV, WUAAG by its constituency of women living with HIV/AIDS and their children, and Kuru by its target audience of San indigenous people. Affiliation with, and representation of these groups was the core component of organisational identity in each instance. In each case the groups, at least at the level of national leadership, had had some contact with rights. In the two Ghanaian cases the dominant understanding of rights was one that was limited and legal and, as such, could only be employed in specific circumstances. In the case of Kuru rights language was seen as both foreign and unnecessarily provocative, particularly in relations with the government.

While each case has its own particularities, some important common themes emerge from this comparison. Among rights-dominant groups, leaders, including founding directors and those who drafted initial organisational mandates appeared to be the most important internal factors, laying the ground for the development of a rights-based organisational culture and the recruitment of rights-oriented personnel. Leadership was a particularly influential feature of frame selection and maintenance in settings where rights language was not contextually dominant. Although there are organisations in each category with charismatic and strong leaders, not all leaders had the same orientation, the same reach, or the same level of interaction and influence on overall organisational identity and frame. For groups with extensive membership and regional offices, for example, there are limited opportunities for a leader's strong rights orientation to be transmitted to other offices or become adopted at grassroots and membership levels in contexts where other frames of understanding are dominant. In contrast, in a small secretariat-based office a strong leader with a commitment to rights is the critical factor in developing and maintaining a rights orientation provided that they are able to access sufficient funding and to recruit others who hold or will acquire a similar orientation. These 'rights

champions’ set a strong course and hold the positions over a long enough period of time to develop a self-sustaining rights culture even after their departure. While not all rights dominant groups were secretariat-based, the one exception, TAC, exists in a context where rights language is popular and domestically dominant. Thus, it is a context where individual interaction with a rights champion is not as critical in establishing or retaining a rights orientation over time.

Among groups at the other end of the spectrum the most important factor affecting frame was not leadership, but the needs, experiences and perceptions of the constituency or membership (people living with HIV, women living with HIV, San people). These personal experiences strongly shaped the selection of frame and the way in which messages were communicated within and beyond the organisation. Groups in the middle mixed category were often influenced by the personal experiences of founders as well as exposure to approaches over time.

Table 4: Intra-Organisational Factors in Frame Selection by Category

Category	Internal Mechanism
Rights Dominant	Leadership/Initial Mandate → rights-based organisational culture/belief in rights among personnel
Rights Mixed	Personal Experiences of Founders + exposure to new approaches → selection of frame
Rights Limited	Personal experiences of membership/constituency → frame chosen that responds to and resonates with constituency (emphasising union and collectivity)

There is variation of the fit of the models outlined above among the cases in each category (with SAfAIDS, for example, being an outlier). In the case of TAC there is also an overlap between the initial leadership and the personal experiences of that leader and the impact of those on the frame.

7.1.2 Extra-organisational Factors Affecting Frame Selection

Extra-organisational factors, including the group's organisational niche in the country or region, connections and interaction with other groups, and the impact of national, regional and international donors play an important role in each organisation's positioning and financial survival, with each of these factors holding potential influence on frame selection and maintenance. At the domestic, or, intra-regional level (ARASA), organisational niche was seen as a benefit of a rights-based approach for two out of three rights-dominant organisations. BONELA respondents viewed their organisation as the only one addressing HIV and human rights, or, from the perspective of some respondents, the only one addressing human rights in Botswana. Rights were not perceived to be a dominant national perspective, nor one that had a history of resonance and success with government. ARASA, also identified itself as having a unique niche and being the only regional HIV and human rights group. ARASA exists in a hybrid environment, with rights the common language in some parts of the region, notably, the regional heavyweight South Africa, and less resonant in other areas. Cultural and political factors at the regional level around frame tended to indicate rhetorical support for rights, where the language was spoken and accepted, but not necessarily understood or operationalised in the way that ARASA envisioned. Respondents noted that support was often there more in theory than in practice. BONELA and ARASA were often the bearers of rights language, usually in broader settings where this was not the dominant discourse. In contrast, TAC exists in a sea of rights language and, while it was unique in initially linking this dominant domestic discourse to HIV, it was more likely to stand out among other South African organisations due to its mobilising capacity or activist use of the law. The domestic anti-apartheid struggle was a critical domestic

context in which TAC was both deliberately and naturally situated as the latest component of an ongoing struggle against injustice.

The groups in this category had a relatively high level of international connection,⁴⁷⁸ although this did not seem to be a direct ongoing source of influence regarding frame use or selection. In BONELA's case, external initiatives, particularly in the form of the United Nations Project Support Document, were critical in the group's formation. The founding director subsequently deliberately sought out international connections, which assisted in the use of the rights frame. Contemporary BONELA employees, however, did not see international connections as influential in the group's use of rights, although current employees joined the group once it had already been firmly established as rights-based. In the case of ARASA, international connections facilitated the group's founding and there continues to be a very high level of international connection. While the transmission of ideas is likely two-way, this group primarily understood this interaction as a conduit for the group to bring a southern African regional perspective, including a strong emphasis on human rights, to international fora. In TAC's case, the frame choice was very locally-based and respondents did not cite international factors as important in the use of human rights.

Table 5: Rights Dominant Organisations: Rights Origin, Context and Organisational Niche

Organisation	Origin of Frame/Exposure to Rights	Rights Context ⁴⁷⁹	Niche
BONELA	International	Rights Limited	Rights, Rights/HIV
TAC	National	Rights Dominant	Mobilisation, Law
ARASA	Regional	Rights Mixed	Regional Rights & HIV

⁴⁷⁸For TAC, at the head office level.

⁴⁷⁹This refers to the environment in which the organisation is located, ie the country or region and predominance of rights discourse in that context.

Among groups in the mixed category, a variety of factors within the country or region were critically influential in frame selection and maintenance. In NACWOLA's case, coalition-building provided exposure to rights as a frame, where collective mobilisation on domestic issues brought together diverse actors. The organisation's niche as the only group of HIV+ women working for HIV+ women also reinforced its internal understanding of identity and influenced the form and frame of advocacy in terms of being explicitly articulated from the perspective and position of women living with the virus. SFAIDS was influenced by the diversity of the region, and cultural norms of dialogue and consultation, emphasising process over frame. For TASO, early domestic prevention campaigns were formative in the initially reactionary frame of 'living positively' which was developed in opposition to the message that 'AIDS kills.'

Groups in this category had a moderate to high level of international connection although in some cases this level of connection varied significantly across offices or categories of personnel. For NACWOLA international factors were critical in spurring the foundation of the organisation, though these were primarily oriented towards women living with HIV. Later campaigns, however, had strong and specific international connections favouring a rights approach. For SFAIDS, international connections were cited as fora in which to share ideas but not sources of frames or approaches. For TASO international experiences, particularly the personal experiences of founder Noerine Kaleeba while her husband was ill in the UK, played an important role in bringing human rights into the organisation. There was also some inconsistent reference to international groups playing a role in connecting TASO to a rights-based approach.

Table 6: Rights Mixed Organisations: Origin of Frame, Rights Exposure and Context, and Organisational Niche

Organisation	Origin of Frame	Exposure to Rights	Rights Context	Niche
NACWOLA	International	International and Regional	Rights Mixed	HIV + Women

SAfAIDS	Regional	Regional	Rights Mixed	Information, Dialogue
TASO	National	International	Rights Mixed	Service, National

Among groups who make very limited use of rights in their advocacy, domestic influences play diverse roles. WUAAG was influenced by the absence of female-only support groups in Ghana as well as experiences of isolation, NAP+ involved a coming together of support groups in response to experiences of stigmatisation, and Kuru was strongly influenced by the treatment and status of the San indigenous people. For these groups, international connections ranged from moderate among head office employees (NAP+) to quite limited (WUAAG, Kuru). WUAAG, like NACWOLA was influenced by early exposure to international groups of women living with HIV, prompting its formation and reinforcing its orientation. NAP+ cited no impact on frame from international groups, and Kuru appeared to have been somewhat swayed away from a human rights approach in part by the rights-oriented international advocacy of Survival International and the negative domestic reaction to this approach in relation to their constituency. Kuru's current emphasis on a 'positive health' approach was also attributed directly to a South African group called Empowerment Concepts.

Table 7: Rights Limited Organisations: Origin of Frame, Rights Exposure and Context and Organisational Niche

Organisation	Origin of Frame	Exposure to Rights	Rights Context	Niche
WUAAG	National	National/International	Rights Limited	HIV + Women
NAP+	National	Unclear	Rights Limited	HIV +
Kuru	National/Regional	National/International	Rights Limited	San

Across these three groups of cases we see some trends and clusters. Among those relying on rights there is variation of sources of frames, and rights contexts, with sources of rights originating from outside of the country in cases where the frame is not domestically prominent. Among these groups niche is often tied to rights (alone or in combination with other factors), and is seldom linked primarily to a population. Among rights limited groups there is a cluster of

national frame origins, rights limited contexts and niche based on group identity. Rights mixed groups show a variety of origins of frame, rights contexts, and niches which feature approaches as well as populations.

Table 8: Organisations by Category: Origin of Frame, Rights Exposure and Context, Organisational Niche

Category	Origin of Frame	Exposure to Rights	Rights Context	Niche
Rights Dominant	All	All	All	Frame or technique oriented
Rights Mixed	All	Regional/International	Rights Mixed	Mix of technique and constituency
Rights Limited	Mostly National	National/international	Rights Limited	Constituency oriented

7.1.2.1 Donors

While not ignoring the clear importance of donors in organisational survival, the data from this project does not indicate that donor pull is the primary influence on the adoption and maintenance of the rights frame. The organisations in this study, reflecting dominant trends in the HIV sector, demonstrate many common features with respect to donors. Although all groups in this study do receive some domestic funding, most of these organisations obtained the bulk of their financing from outside of the country, mostly from non-African sources. Reflecting the broader reality of the HIV NGO sector in sub-Saharan Africa, this funding is predominantly through bilateral development assistance, multilateral development assistance and private foundations (see Birdsall and Kelly 2007, Kelly and Birdsall 2010) with some local funding from government and occasionally local businesses or foundations. Domestic government funding is typically limited and used to fund service provision rather than advocacy, a trend that is reflected in this study. Selecting organisations receiving exclusively domestic funding, while an effective way of controlling for external financial influence, is very difficult and would likely have resulted in a distorted sample focusing on very small, local organisations involved almost

exclusively in service provision (for example, village-based home-based care, orphan care, support groups, funeral cooperatives). The organisations examined in this study do, however, demonstrate variation in the degree of domestic funding, include groups that are highly local (WUAAG, Kuru) and, while all groups provide some form of service (legal clinics, advocacy training, HIV testing, medical care, small loans, support groups), these organisations also offer considerable variation in the service to advocacy ratio. The advent of project-based funding, which is typically “short-term and project specific” (Birdsall and Kelly 2007, 2) means that all groups studied reflect the common pattern of multiple donors. The decline of comprehensive operational funding, and the rise of patchwork project funding, also lessens the likelihood that any individual donor will hold a strong influence on overall organisational frame. This reality also means that groups can and do target specific projects to donors with aligning interests and, that donors may do the same by selecting groups already operating in their area of focus.

Among rights-oriented groups international funding was dominant, although all groups also received some domestic or regional funding.⁴⁸⁰ Rights dominant organisations had donors with a variety of frame orientations including, but not restricted to, rights. Groups in this category saw donors as generally partial to rights-based advocacy, although BONELA respondents recognised a divide between US-based donors (primarily government donors USAID and PEPFAR) and EU donors with the latter being more favourable to a rights approach in relation to HIV. In line with this perception, respondents reported targeting projects to donors with specific areas of focus. Groups would, for example, choose to submit proposals to European donors for rights-based

⁴⁸⁰ In the case of ARASA, a regional organisation.

projects as well as for projects involving sex work and other topics that were considered controversial by US government affiliated donors.

All organisations in this category witnessed changes in their funding over time, changing donors as projects completed and as funding mandates ended or shifted. This included moving from donors with a primarily rights orientation to ones with other areas of focus and vice versa. If donors were the primary influence on frame use, we would expect to see fluctuation of frame in line with, or shortly following, changes in funding. This would be most likely to appear in newsletters and press releases as these reflect current activities and areas of emphasis. Yet, an analysis of such materials across the three groups did not show a fluctuation in rights that shadowed changes in funding. Favoured international discourse around HIV also varied over time, with a BONELA respondent noting a dip in support for rights circa 2004, where “[f]or a few years there was this total avoidance of using human rights language”⁴⁸¹ followed by a resurgence. Again, this pattern was not reflected in organisational use of the rights frame.

Respondents from BONELA and ARASA reported that donors generally favoured a human rights approach, while TAC respondents did not cite a donor preference with regards to frame. No respondents reported a donor influence on their organisational frame. Although it might be unexpected for respondents to report such an influence in interviews, the topic of funding was an area where respondents tended to be particularly candid, often highlighting frustrations and gaps. Respondents readily reported other forms of pressure, suggestion or influence from donors. ARASA respondents, for example noted that it was most useful to work with donors that were

⁴⁸¹ Author’s interview, Christine Stegling, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 24 January 2011, Brighton, United Kingdom.

familiar with them and with Southern Africa, commenting that some donors pushed for styles of advocacy that were not considered effective or appropriate for the region. A BONELA respondent described some projects as “donor driven”⁴⁸² reporting along with several other respondents that the group was sometimes approached by donors who sought an NGO partner in BONELA’s area of work. Donors, in this instance came with project ideas, stating, for example, “we have funding to do 1, 2, 3, 4 and we know these are issues of interest to you. Would you like to work on it?”⁴⁸³ In so doing, donors occasionally introduce new areas of work falling within the organisation’s existing rights frame.

Organisations appeared aware of the potential pitfalls of poor donor choices, and, in TAC’s case, cognisant of the perils of actual or perceived influence. A BONELA respondent, for example, warned that, “if you accept [PEPFAR money] to fund [work on] sex work know that it’s going to limit you here and here. [...] So you need to be careful. Maybe it’s not right for a human rights approach.”⁴⁸⁴ ARASA respondents emphasised the importance of a good fit with funders, stating a preference for “donors who have actually come and spent a lot of time in this region and really understand the work that we do and why it has an impact.”⁴⁸⁵ TAC made the clearest statement of all with strong wordine on its website declaring that funding from specific sources such as pharmaceutical companies and the US and South African governments, who were judged to imperil their impartiality, would not be accepted. Given the frankness of respondents with respect to the politics of donor funding, I would expect them to report donor influence on frame if they were aware of this occurring.

⁴⁸² Author’s interview, Employee 3, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 28 June 2010, Gaborone, Botswana.

⁴⁸³ Author’s interview, Employee 3, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 28 June 2010, Gaborone, Botswana.

⁴⁸⁴ Author’s interview, Anna Mmolai-Chalmers, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 29 June 2010, Gaborone, Botswana.

⁴⁸⁵ Author’s interview, Michaela Clayton, AIDS and Rights Alliance for Southern Africa (ARASA), 29 July 2010, Windhoek, Namibia.

Rights mixed and rights limited groups tended to have mostly international donors with heterogeneous frames including rights. Among rights mixed groups, NACWOLA and SAfAIDS had predominantly international non-African funders, while TASO worked in partnership with the Ugandan government and international donors including significant US funders. NACWOLA and SAfAIDS each had some rights-oriented donors but did not report pressure to use the rights frame. Some TASO respondents noted a current positive rights association among donors. Among rights limited groups NAP+ had primarily international donors, with no suggestion of a favouring or disfavouring of rights. WUAAG had a mix of African and international donors, with a larger number of national donors than other groups. Kuru, like TASO, had a higher level of cooperation with domestic government who primarily supported service provision in both cases, but both were also funded by international donors with mixed frames. Kuru, however, also received a significant proportion of its funding from SIDA, a donor with an overt rights emphasis. As the only group to report a decision not to refer to rights in advocacy, we might expect tensions with SIDA on this topic, however, none were reported.

In the chart below bolded text indicates a rights-dominant donor, underlined text indicates rights mixed, and regular text indicates a non-rights based approach. Donors listing rights as a key component of their mandate are classified as rights-dominant, those with reference to rights that appears subordinate or equal to other objectives are classified as rights mixed, and those who contain no reference to rights in their objectives are considered non-rights based.

Table 9: Donors and Rights Orientation

Category of NGO Recipient Organisations	International Donors	National / Regional Donors
Rights Dominant (BONELA, ARASA, TAC)	AIDS Fonds American Embassy – Botswana Atlantic Philanthropies BOTUSA/PEPFAR Bread for the World	AIDS and Rights Alliance of Southern Africa (ARASA) AIDS Foundation South Africa Botswana National AIDS Coordinating Agency Centre for the Study of AIDS at the University

	Canadian HIV/AIDS Legal Network DFID Finnish Embassy HIVOS Human Rights Internet (HRI) Interfund Irish AID Medecins Sans Frontieres Netherlands Institute for Southern Africa (NIZA) Open Society Institute/ OSISA Schorer Foundation SIDA/Forum Syd Stephen Lewis Foundation The Ford Foundation The John Lloyd Foundation Tides Foundation <u>UNAIDS</u> UNDP World Health Organisation World University Service of Canada (WUSC) Xtending Hope	of Pretoria Ethics Institute of South Africa Government of Botswana Botswana Ministry of Finance in collaboration with the European Union Public Welfare Foundation The Media Institute of Southern Africa
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Table 9: Donors and Rights Orientation

Category of NGO Recipient Organisations	International Donors	Local/ Regional Donors
Rights Mixed (NACWOLA, SAfAIDS, TASO)	Action Aid <u>AWDF</u> CDC CIDA Comic Relief DANIDA DFID European Union Gtz Health Link UK HIVOS Interact Worldwide UK Irish Aid John Snow International Management Science for Health Norwegian Council for Africa Oxfam Canada Peace Corps Save the Children Uganda SIDA <u>UNAIDS</u> UNDP United Nations Fund for Women USAID VSO World Food Program	Uganda AIDS Commission Uganda Ministry of Health

Rights Limited (NAP+, WUAAG, Kuru)	Action Aid AED Sharp <u>AWDF</u> Catholic Relief Services CIDA DFID <u>Global Fund for Women</u> HACI Netherlands Embassy North American Women's Association Peace Corps SIDA Skill Share Stephen Lewis Foundation <u>UNAIDS</u> USAID WUSC	Botswana Ministry of Health Coca-Cola Bottling Company – Ghana Ghana AIDS Commission Ghana National AIDS Control Programme Nugouchie Memorial Medical Research Institute – University of Ghana Opportunities Industrialisation Centre International (OICI) <u>Pro-Link</u> Rescue Mission Ghana Society of Women Against AIDS – Ghana
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While rights-based groups were most likely to indicate that their donors had a positive association towards rights, and groups with a higher level of local and government involvement in funding tended to have a lower use of rights, these associations were slight as groups on either end of the spectrum had shared donors. Three donors funded groups in each category: SIDA, with a strong rights orientation, UNAIDS with some rights mention and DFID with development and poverty reduction orientation. Groups in the rights dominant category had more overtly rights oriented donors, with HIVOS and OSI/OSISA appearing prominent in this category and less so in others.⁴⁸⁶ Groups in the rights mixed category show a wide spread of donors and frames while groups in the rights limited category have a greater proportion of national funders, including their own governments.

The donor dimension, while crucial to the existence and survival of each of these organisations, does not appear to be the critical factor with respect to frame selection. While donor support or, at least, non-opposition to organisational frames is important, there is limited evidence that

⁴⁸⁶It is important to note that some of the funding-frame correlations are effectively acting as a proxy for geography as some donors only operate in Southern Africa (OSISA) and some work in some countries not others. Hence, while Southern African groups are more likely to use rights, they are also more likely to have common funders due to geography.

donors, in the case of these organisations, are succeeding in pulling organisations towards or away from particular frames, including rights. Donors tend to change frames and priorities more often than the groups they fund. As noted earlier, the shift away from operational funding⁴⁸⁷ towards project-based funding has reduced the leverage held by donors as their influence is limited to the particular project they fund. In this context, donors did prompt projects for some groups, as well as initiate alliances among groups they funded. Organisations generally tend to seek out donors with concordant frames, and donors also often make efforts to identify and work with organisations with frames or projects that mesh with their ethos. As Nelson and Dorsey argue, groups themselves can sometimes serve as a pull on international NGOs noting that the “dynamism” of groups such as TAC “make [...] it essential for international NGOs to be associated with them, and whose strategies lead international NGOs towards human rights-based approached to major social policy issues” (Nelson and Dorsey 2008, 154). In this project I did not encounter recipients exercising a pull on donors, however, I did find accounts of donors being drawn to and compelled to work with particularly successful and dynamic groups.

7.1.3 Impact

It is logical to suspect that at least part of the motivation for selecting a particular frame is the belief that doing so will provoke the desired impact from government, donors, or recipients. Advocacy groups aim to be effective in their work and to choose strategies that achieve the result they seek. These often exist on multiple levels and in multiple locations, including changing government law, policy or practice (either nationally or locally), shifting donor priorities, and influencing the behaviour of recipients with reference to infection (ie risk behaviours), accessing

⁴⁸⁷Where one donor funds the majority of key areas of operation including salaries, rent, vehicles, communications.

of services, and claiming of rights.⁴⁸⁸ In many of these areas of impact there is a lack of systematic assessment⁴⁸⁹ and, as a result, impressions of impact may be based on personal perceptions of employees in each organisation. While such perceptions of impact are not objective data they can and do motivate the use and selection of frame.

Among rights dominant organisations, rights are understood as linked to impact particularly on an individual level in the form of empowerment. All three groups articulated very similar perceptions of impact on the ability of individuals to claim health care services. Respondents stated that “knowledge of rights and entitlements, it’s very, very empowering,”⁴⁹⁰ “I have the right to demand better”⁴⁹¹ and “it’s my constitutional right, doctor.”⁴⁹² Rights are seen as an important trigger enabling those living with HIV to claim their rights, particularly in health care settings, from a position of knowledge and strength. There are some nuanced distinctions between perceptions of rights and impact between the three groups. BONELA respondents view their impact as individual, while TAC respondents see individual impact that is also backed by the potential of collective mobilisation. TAC views rights as holding the backing not only of mass-mobilisation but also of the law and, in contrast with all other groups, made frequent and specific reference to their country’s constitution. In addition to individual empowerment, ARASA made strong linkages between human rights and process, highlighting consultation and engagement as critical in impact and outcomes.

⁴⁸⁸In many instances in the health care sector these last two categories frequently overlap, however, advocacy also targets instances of eviction, job lost and rumour-mongering which entail rights claiming, but may not involve accessing services.

⁴⁸⁹Doing so may be beyond the capacity of a particular organisation and also is the type of activity that is difficult to fund.

⁴⁹⁰Author’s interview, Anna Mmolai-Chalmers, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 29 June 2010, Gaborone, Botswana.

⁴⁹¹Author’s interview, Employee 1, AIDS and Rights Alliance for Southern Africa (ARASA), 8 August 2010, Cape Town, Western Cape, South Africa.

⁴⁹²Author’s interview, Employee 5, Treatment Action Campaign (TAC) Ekurhuleni District Office, 25 August 2010, Ekurhuleni, Gauteng, South Africa.

Among rights mixed groups respondents linked a number of factors to impact which did not always have connections to frame. NACWOLA respondents emphasised collaboration as critical for impact. Similarly, TASO respondents highlighted collaboration with other NGOs and government as being critical for success. SAfAIDS, somewhat like ARASA, placed an overwhelming emphasis on process, highlighting the method of advocacy over the message and placing particular emphasis on the importance of consultation and dialogue. Impact is also tied to some extent to organisational identity, with NACWOLA understanding their voice, one of women living with HIV, as having a more profound impact on decision makers than more detached advocates. Similarly, SAfAIDS respondents see their position as distinct from the more emotional voices of the support groups they work with viewing their role as “produc[ing] information to produce advocacy.”⁴⁹³

Among rights limited groups, need and vulnerability are more prominent than among other groups with emotional expressions of need and vulnerability seen to be a key factor affecting impact. NAP+ respondents highlight stories that ‘touch the heart’ and chronicle the journey from vulnerability and stigma to recovery, and WUAAG also highlights vulnerability and need in campaigns directed at the government. The two groups also hold a narrow and specific understanding of rights, associating it with law and specific government agencies. Kuru is the only group with some negative association with human rights, choosing an approach with local cultural linkages and terminology that resonates with domestic government.

Table 10: Beliefs about Impact

⁴⁹³ Author’s interview, Employee 1, Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), 12 August 2010, Pretoria, Gauteng, South Africa.

Category of Organisation	Beliefs about Impact
Rights Dominant	rights → strength → impact
Rights Mixed	Appropriate process → impact
Rights Limited	Need/vulnerability → impact

The three categories illustrate different beliefs about advocacy and impact. Among rights based groups, rights are seen as bringing power and the ability to act to individuals, and are viewed as a critical catalyst. Interestingly, the primary impact of rights is seen as individual and internal, rather than oriented at government. In two of the three groups the use of rights is not linked to mobilisation. That is to say, groups believe that a chief benefit of rights is the impact on the individual and on their ability to identify and claim their rights as an individual. This differs from rights as a rallying call, or rights as a language of mobilisation, a concept that was evident with TAC, but appears in all cases to be subordinate to an individual-level internal impact.

When it came to questions of impact among the rights mixed group, respondents were far more likely to list process or methods of advocacy as critical factors rather than anything that could be identified as a frame. These groups emphasised the importance of ‘how’ advocacy was conducted over the ‘what.’ Organisations in the rights mixed category most often discussed impact at a variety of levels, including community level and at the level of national government. The dominant discourse in two of three of the rights limited groups is one grounded in personal experience highlighting need and vulnerability. These personal and emotional connections emphasising the consequences of funding shortages and inequitable policies were cited as key factors influencing the opinions and actions of community members and governments.

With nine diverse cases, the categorisation described above fits some cases more closely than others. ARASA illustrates the connections between rights dominant and rights mixed, with respondents reflecting on the empowering impact of rights, but also noting the importance of

process in impact. Kuru, as the lone case with an actual aversion to rights also differs slightly from other cases in the rights limited category as accessibility and political palatability are the most important factors for this group.

7.1.3.1 Campaigns

Campaigns are one component of impact that allow for exploration of whether some topics lend themselves better to human rights based campaigns. The nine groups examined conducted a variety of campaigns of which only a small sample were examined in detail. As such, these can suggest trends between frame selection and fit with issues, but cannot show clear correlation. Campaign topics of rights dominant groups included condoms in prisons, an HIV employment law, funding for health, prevention of mother to child transmission (PMTCT) and criminalisation of HIV transmission. Although each of these clearly link to state behaviour, law, policy or funding in some way, campaigns on two topics, condoms in prisons and PMTCT, made direct connections between the lack of action on the part of the state and infection or death of its citizens. With a short chain between the action and the impact, clear linkages to the state and an impact that is obvious, severe and results in bodily harm, these campaigns fit the criteria of the types of campaigns in which rights claims are likely to be effective (Keck and Sikkink 1998; Sundstrom 2005, 419-449). Campaigns against criminalisation are more complex in that there are actual and potential rights violations and arguments on both sides, on the side of the person who could infect, and on the side of the person who could be infected. The campaign on this topic is very much in line with the health and human rights discourse, arguing that criminalisation makes people less likely to test, penalises the most vulnerable, particularly women, and, in pushing open discussions about HIV underground, increases the risk of infection. Finally, the campaign for resources for health has more challenging linkages to human rights.

Here, the campaign is not against the state, but, in a sense, for the state, trying to increase health funding by calling upon national and international sources and making linkages between infrastructure and health care outcomes. The use of rights, however, does not follow the outline described above. BONELA relied on a mixed public health and human rights approach with regards to condoms and prisons due primarily to the topic's political sensitivity, while using rights in a more direct manner on the HIV and employment law. TAC used rights prominently on PMTCT, but also made an effort to frame resources for health as a rights issue, even though this is not the dominant frame used. ARASA similarly drew strongly on rights, in conjunction with gender on the topic of wilful criminalisation while using rights and other approaches with respect to resources for health.

In the rights mixed groups, topics and connections appear to be the most important factors in the framing of campaigns. For NACWOLA, the initiative of a UK volunteer with a background in child rights began a new area of programming in that field. With respect to the group's work on the HIV/AIDS Prevention Bill, gender and human rights were dominant and, with respect to rights, domestic coalitions and international connections played a key role. In the case of SFAIDS the rights frame appears to originate from local consultation in the case of the policy dialogues, and is impacted in part by the legal framing of the stated objectives. The rationale for rights is less clear in the 'changing the river's flow' campaigns which targets domestic violence.

While reasons are diverse among the rights limited group, the overwhelming theme in outward-oriented advocacy is that of need. Both WUAAG and NAP+ have had various campaigns on access to ARVs in which they highlighted need and fairness (in relation to other health conditions). With respect to anti-stigma work a personal touch and sympathy were highlighted as

approaches which tugged at the heart strings. For Kuru, access was a language used when targeting government, and unity the main theme when targeting the community, in both cases the approach strongly informed by the message's recipient.

7.1.4 Conclusions: Comparing Across Categories of Cases

Although each case is distinct some patterns are visible when comparing across categories of cases (rights dominant, rights mixed, rights limited). Examination within these topic areas has not considered the relative weight of each factor on frame selection. The rights dominant group appears to have heavier influences from within the organisation, and frame is often justified on a basis of belief. The rights mixed group illustrates the impact of external interactions on frame. The rights limited group is primarily influenced by its constituency with respect to frame.

7.2 Comparing Across Themes and Variables

This section examines themes and variables that emerged from the research focusing on: (1) organisational identification and structure, (2) understanding of human rights, and (3) origin and sustenance of rights. Issue-based organisation identification and secretariat-based structures are more likely to align with rights dominant groups, while less rights oriented organisations tend to hold constituency-based organisational identities and more membership-based structures. Broad understandings of rights are associated with rights dominant groups who are also more likely to experience rights as belief, while topical or limited legal understandings are prominent among groups who make less use of rights. While origins of rights are diverse across and within categories of groups, exposure at the level of leadership is important, as is the ability to develop support for the frame through personnel and funding.

7.2.1 Organisational Identification and Structure

Organisational identification and structure are two factors that emerge from the data and have an apparent connection with the use and non-use of the human rights frame. Issue-based identification and secretariat-based structures appear to correlate with rights dominant groups, while constituent-based identification and a membership-based structure is more common amongst the other two categories.

Groups that hold primarily constituent-oriented identifications are less likely to consistently use the rights frame. NACWOLA, TASO, NAP+, WUAAG and Kuru all have organisational identities that are explicitly constituency-based, with their identification tied to a group of people, rather than an issue or topic. The majority of these groups primarily identify as organisations of HIV positive people, with two having their identity tied to being groups of HIV+ women. BONELA, TAC, and ARASA primarily identify as issue-based organisations targeting particular topics or areas of intervention. For BONELA and ARASA their primary identification is human rights. TAC is perhaps the closest to a hybrid of a constituency and issue based group. Well-known for its ‘HIV positive’ t-shirts and activist membership, the group while firmly grounded in its constituency, holds treatment access as the cornerstone of its organisational identity. SAfAIDS identifies primarily with an approach (provision of information).

These trends in organisational identification have consistent correlations reflected in organisational structure. Among the groups with a primarily constituent-oriented identification, five have membership of people living with HIV as a very significant part of their organisational structure, membership and direction (TAC, NACWOLA, TASO, NAP+, WUAAG). Each of

these groups is membership oriented, with four (TAC, NACWOLA, TASO, NAP+) having a national presence including a head office, regional offices, and some form of local committee or community-based presence.⁴⁹⁴ Several of these groups often see movement between membership and employment (TAC, TASO, NAP+), and all have support groups and support as an important component of their existence. TAC, while categorised as more of an issue-based group (but with strong ties to constituency), also fits the profile and organisational structure of these membership-oriented organisations.

With the exception of TAC, the groups with an issue-based orientation (BONELA, ARASA) were more likely to be secretariat-based groups with primarily organisational rather than individual membership. These groups were somewhat less likely to draw their staff directly from their constituency⁴⁹⁵ and more likely to hire new employees from outside of the organisation based on professional qualifications rather than voluntary involvement with the group.⁴⁹⁶ In the two secretariat-based cases the groups were initially established with one employee, a founding director, as opposed to a group of people coming together in the community. In each case the founding director was also a non-citizen, which may have impacted on the structure of the organisation, as may their respective educational and experiential backgrounds. In both cases the groups have increasing memberships,⁴⁹⁷ growing grassroots

⁴⁹⁴WUAAG is a smaller single office organisation located in metropolitan Accra.

⁴⁹⁵Although in both instance this did occur it was a smaller proportion of staff and less likely to be people who had worked their way up from membership.

⁴⁹⁶This is not to suggest that there is not overlap between constituency and qualification. In particular, there are clearly many people living with HIV who are very well qualified through formal education and life experience who are in leadership roles in many of these organisations. All groups studied had some staff with very high levels of education and qualification, typically lawyers and social workers. These two groups were less likely to have individuals join as members and gradually come to leadership positions within the organisation.

⁴⁹⁷BONELA has more than 200 with a shift from predominantly organisational members to predominantly individual members, however, it is not a membership-driven organisation and has limited consultation. ARASA has more than 50 organisational members.

connections and increasingly diverse representation within their ranks. Thus these ‘one woman shows’ have grown into secretariat-based organisations with an increasing local presence.

While rights may not have led to the structure of the group, it does appear, as discussed in section 7.1, that a secretariat-based structure allows for dissemination and inculcation of a rights-based frame within an organisation, if it is led by a ‘rights champion.’ Both of these groups were very small for many years and this allowed for regular interaction with leaders, and recruitment tightly connected to this ethos, over time consolidating a niche based on rights. In a more diffused organisational structure, particularly in a setting where rights discourse is not dominant, it would be difficult for a leader to develop and maintain a rights-based organisation. Thus, a leader with a strong rights organisation is able, even in relative isolation, to build a rights-based organisation.

Table 11: Organisational Identification and Structure

Organisation	Category	Primary Organisational Identification	Organisational Structure
BONELA	Rights Dominant	Human rights	Network of Organisations and Individuals
TAC	Rights Dominant	Treatment access	Individual Membership Based
ARASA	Rights Dominant	Human rights	Partnership of Organisations
NACWOLA	Rights Mixed	HIV + Women	Individual Membership Based
SAfAIDS	Rights Mixed	Information Provision	Non-Membership
TASO	Rights Mixed	Service, HIV+	Individual Membership Based
NAP+	Rights Limited	HIV+	Individual and Organisational Membership Based
WUAAG	Rights Limited	HIV+ Women	Individual Membership Based
Kuru	Rights Limited	San	Non-Membership, Family of Related Organisations

As the discussion above suggests, there appears to be a correlation between rights orientation, issue-based organisational identification and secretariat-based organisational structure. Skocpol has examined the transition of groups from membership based organisations, to advocacy groups with professionalised staff and more top down methods, noting that over time these groups’ memberships have dwindled, and tight personal associations, and “fellowships organisations” (Skocpol 2003, 7) have become, as she and Fiorina argue, loose donation-based relationships in a

“remarkably oligarchical” “new civil universe” where “advocacy groups are staff-heavy and focused on lobbying, research, and media projects ...[and] managed from the top with few opportunities for member leverage from below” (Skocpol and Fiorina 1999, 499). In concert there has been, they argue, a shift from “doing with” to “doing for” (Skocpol and Fiorina 1999, 502). In examining the American feminist movement of the 1960s and 1970s, Gelb and Palley reach similar conclusions, noting that a broad social movement developed into a “stage of political development that emphasised interest-group organisation and professionalisation” and tended to be based around leadership rather than membership (Gelb and Palley 1982, 14).

As discussed earlier, the split between membership-based and professionalised leadership-based groups is a key structural feature of the organisations examined. However, there are several key distinctions from the scenario described by Skocpol and Fiorina and Gelb and Palley. First, there does not appear to be a trajectory whereby groups begin as membership-based and evolve into leadership-based groups. Groups tend to begin as one or the other (or a hybrid), usually increasing membership over time. While there does appear to be a connection between rights-based groups and more secretariat-oriented organisations with strong leaders, membership based groups with a change in leadership who bring in a rights-based approach do not result in diminishing membership. Rather, it seems more likely that the group experiences a growing disjuncture between the leadership-based and rights-oriented head office, and the non-rights oriented membership based throughout the region or country. NAP+ is one possible example of this, with NACWOLA also potentially falling into this category.⁴⁹⁸ A second option is that the

⁴⁹⁸Interviews were not undertaken outside of the head office with NACWOLA.

group may find a way to spread rights through its membership, something that TAC, while domestically supported by a rights discourse, has been very successful in doing.

While in some cases bright lines can be drawn between ‘professional’ and ‘membership’ employees, in several instances there are people who could qualify just as easily under either heading, having for example completed formal qualifications and then approached the organisation after being diagnosed HIV positive (or vice versa). Second, the distance between membership and beneficiaries, and between “doing with” and “doing for” is also, I would argue, smaller among these cases than in Skocpol and Fiorina’s research. Distinctions between general public interest-based claims and self-interest of membership may be somewhat academic, in countries with high prevalence rates. Is action on behalf of 20 – 30 + % of the workforce not in the public interest? In societies emphasising extended family ties, where does ‘self interest’ end, particularly in a context where the vast majority, in some settings virtually all, families are affected by HIV? Rather than defining the tenuous line between these overlapping groups, it useful here to return to the frame of human rights and to examine this choice of language as an effort to shift specific individual experiences and claims (‘this is my story’) to more than a “systemic problem” (Sperling 1999, 54), but rather a broad call to the public interest of human rights and dignity (‘we, as humans, have this right’). This shift, as explored further in the next section, is more accessible to those with less direct experience who exist in larger numbers in secretariat-based organisations, as it draws on a broader pool of inclusivity.

7.2.2 Understanding of Human Rights

Perceptions of rights vary significantly between groups who use rights as a dominant frame and those who employ it more sparingly. Rights dominant groups generally understand rights as

broad, flexible and accessible, including elements of both approach and outcome. Among groups in the mixed category, rights are predominantly seen as topics rather than broad frames, while rights limited groups often express a specific, limited and legal understanding of the concept. A second important distinction is the role that belief holds among respondents from rights dominant groups. This level of personal connection is not evident in the rights mixed and rights limited groups and is without a parallel among other frames.⁴⁹⁹

7.2.2.1 Rights as Expansive or Limited

Rights are understood as taking multiple forms among groups using them as a dominant frame. These organisations see human rights as holding a relationship with, but not wedded to law. Groups often use the language of rights in several different ways, including rights as legally enshrined entitlements, right as goals or outcomes, but also ‘rights-based approaches’ which necessitate high levels of engagement and participation but do not necessarily include a strong emphasis on the use of rights language. Human rights are understood as a mega frame, with other topics, including health and gender, fitting within it.

Rights are also perceived as playing a variety of roles in influencing organisational decisions, campaign selection and structure and behaviour. BONELA respondents feel that holding a rights perspective shapes organisational choices, with respondents commenting that being a rights-oriented group entails looking at different or sensitive issues, particularly those pertaining to vulnerable populations. Connections between rights and ideas of process receive heavy

⁴⁹⁹From this data it is difficult to discern whether this particular enthusiasm and connection to rights is distinctly linked to qualities of the rights frame, or if, for example in a different time (the 1980s, the heyday of African development) or place (in a professional public health setting) one might find people with similar personal dedication to other frames. However, as Priya Bala-Miller suggested, rights may be unique from at least these two frames in that it can be less easily co-opted by industry or the state, nor is it necessarily housed in either.

emphasis among ARASA respondents engaged directly in advocacy programming. Highlighting elements of process, one respondent noted “[o]ur focus is entirely on promoting a human rights-based response to HIV in the region through training and capacity building and advocacy around HIV and human rights and TB now as well.”⁵⁰⁰ While rights are not always the advocacy frame used, the ‘rights-based approach’ involving high levels of community involvement is employed in each case. Respondents emphasise the importance of ownership among the community as “they’re the ones who will actually pull the advocacy together”⁵⁰¹ and view rights-based advocacy as primarily a project of capacity building. TAC respondents make a strong connection between education and rights claiming. A common turn of phrase in TAC’s mission is that they exist to “make sure”⁵⁰² that laws or policies are respected at a local level. This terminology is very much in line with the practice of TAC’s advocacy where the process of rights claiming is described as enforced monitoring and where the emphasis is on equipping people at the grassroots who experience or witness rights violations with the skills to advocate for rights directly using the TAC structure.

Groups in the mixed category hold a slightly more compartmentalised view of rights, with rights less frequently seen as an over-arching perspective and more often seen as a topic, which may be employed in some instances but not others. Among two groups in this category, SAfAIDS and NACWOLA, rights are predominantly linked to gender, in the latter case due to organisational focus, and in the former case because of perceived fit between the concept and the topic. Among TASO respondents, rights are linked to concepts of stigma and discrimination.

⁵⁰⁰ Author’s interview, Michaela Clayton, AIDS and Rights Alliance for Southern Africa (ARASA), 29 July 2010, Windhoek, Namibia.

⁵⁰¹ Author’s interview, Employee 3, Treatment Action Campaign (TAC) Head Office, 17 June 2010, Cape Town, Western Cape, South Africa.

⁵⁰² Author’s interview, Employee 5, Treatment Action Campaign (TAC) Ekurhuleni District Office, 25 August 2010, Ekurhuleni, Gauteng, South Africa.

Among rights limited groups, two of the three groups hold a procedural and legal understanding of rights, seeing it as a specific and limited concept relating to enforcement mechanisms. Among NAP+ Ghana and WUAAG respondents, rights are commonly understood as having a specific meaning usually grounded in law, with the term rights itself frequently understood as being a near synonym for specific enforcement mechanisms. In-line with this view, WUAAG respondents view particular advocacy topics as inherently, or factually connected to the rights frame, expressing the opinion that rights language could only be legitimately employed for claims with a clear basis in law, noting “‘If it’s not in the law, it’s not a rights issue.’⁵⁰³ Rights messages are understood as concrete, specific, non-ideational outcomes and are generally understood as the act or mechanism of enforcement. In the third case, Kuru, rights are primarily viewed as foreign and inaccessible, so much so that the term does not have a proximal equivalent in the local language.

The process of referencing rights, as examined above, can and does mean many different things. While often understood as narrow, specific, defined and legal by rights limited groups, and as a topic by rights mixed organisations, those in the rights dominant category understand rights as a much broader process. While rights claiming can be seen as “a statement of fact that should compel assent,” such as a quoted law or regulation, it can also be seen as “a performative practice of persuasion, [which] provides an opportunity for individuals and groups to form and share ways of seeing the world; to shed light on and reimagine ways of thinking, being and doing; and to take an active role in the political life of the community” (Zivi 2012, 115). This

⁵⁰³ Author’s interview, Lydia Asante, Women United Against AIDS (WUAAG), 19 February 2010, Accra, Ghana.

performative practice “creates and contest[s] the boundaries of community and the meaning of identity,” in the context of HIV/AIDS questioning and “challeng[ing] our understanding of who is a member of the general rights-bearing public” and creating new forms of political subjectivity (Zivi 2012, 90, 92). It is a “process where people who have no place or voice in a political community act as though they have both and, in doing so, shift the basic understandings and boundaries of that community” (Zivi 2012, 92). The use of rights in the context of HIV, Zivi argues with reference to HIV positive mothers (Zivi 2012, 99), and here I argue more broadly, is a process of calling to inclusion by affirming identities not as the outsiders that society in fear and stigma had initially made them out to be, but as full members, as citizens, and as people.⁵⁰⁴ Thus rights claims can be a way of asserting belonging and identifying themselves as ‘part of’ rather than ‘apart from’ society.

The process of becoming involved, either as a member or as staff, with an organisation can also entail “a process of transformation of consciousness,” Sperling argues, whereby, “they recognise and name discrimination against a societal group, often ‘framing’ the injustices they face differently than does the society in which they live” (Sperling 1999, 54). This process of distinctive naming, which is the case in all contexts, save South Africa where rights discourse is quite common,⁵⁰⁵ may also be connected to the concept of empowerment, which was widely seen by rights dominant organisations as the main output of a rights approach. The idea of claiming, or re-claiming terminology or identity has been important in many struggles,⁵⁰⁶ and, in the context of HIV has often involved voluntary labelling (TAC’s HIV positive t-shirts), and

⁵⁰⁴While some of the organisations studied also campaign on non-citizens they have tended to run into greater challenges in doing so.

⁵⁰⁵However, even in this case it was TAC’s innovation to link this language to HIV/AIDS.

⁵⁰⁶Including the reclaiming of words with a conventionally pejorative meaning by racial and sexual minorities, for example.

terminology which emphasises life and strength (ie ‘living with’ rather than ‘suffering from,’ ‘positive living’). Choosing rights then, over paradigms and language of pity and infection is a way to challenge perceptions, to re-categorise and to claim an entitled belonging in the societies in which they live.

7.2.2.2 Rights as Belief

Human rights as belief is one perspective on rights that surfaces repeatedly among rights dominant groups, with several respondents commenting on a “transformation of consciousness” (Sperling 1999, 54) spurred by interaction with rights discourse. Rights as belief is a dominant concept among BONELA respondents, and apparent but not dominant among ARASA respondents. BONELA respondents articulate a high level of belief in rights, viewing it as an expansive concept or philosophy, with comments such as “human rights are the reason why we exist, right?”⁵⁰⁷ The idea of rights as beliefs is also evident among some ARASA respondents, with the founding director referring to “advocacy based on principle”⁵⁰⁸ even if the results of impact on health are unknown. Rights are viewed as less ideational and more concrete among TAC respondents, with their utility based on the existence of violations, and, conversely the presence of constitutional guarantees.

Respondents in rights dominant groups often held deep individual connections with human rights frequently giving lengthy passionate responses describing human rights as core to their dignity, identity and “inherent to existence as a human being.”⁵⁰⁹ Rights are depicted as a strong belief

⁵⁰⁷ Author’s interview, Program Manager, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 28 June 2010, Gaborone, Botswana.

⁵⁰⁸ Author’s interview, Michaela Clayton, AIDS and Rights Alliance for Southern Africa (ARASA), 29 July 2010, Windhoek, Namibia.

⁵⁰⁹ Author’s interview, Program Manager, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 28 June 2010, Gaborone, Botswana.

and worldview almost akin to a secular religion (Hopgood 2006; Reader 2003, 41-51). This parallel, while seldom at the forefront of human rights discourse, is not new. As noted in Chapter 2, Amnesty International (AI) founder Peter Benenson stated that the group existed to “[r]e-
kindle a fire in the minds of men” and “give him who feels cut off from God a sense of belonging to something greater than himself, of being a small part of the entire human race” (as cited in: Buchanan 2002, 93-594). While the groups studied do not have the global reach of AI, nor its almost ritualistic procedures and lexicon, belief in rights remains very important and has a hold over adherents that is qualitatively different than that of other frames such as development or public health.

In contrast with AI, where the distance between advocates and beneficiaries can be vast, and where the structure of the organisation does not generally permit campaigning on behalf of oneself, a group to which one belongs, or one’s country, most of those involved with the groups in this study live alongside the issues on which they campaign. These issues campaigned on are in their own country, neighbourhood, family, and often their own bodies. Reflecting on Durkheim, Hopgood notes that, in such circumstances, the sacred may be nearby. He states:

human beings create meaning for themselves through their collective endeavours, especially when these concern emotionally potent life experiences such as death and suffering. A spirit is generated that makes the whole seem more than the sum of its parts. We are at our best, and our worst, when we are organised together for action because we are at the closest point to the threshold between the sacred and the profane, between meaning and day-to-day existence (Hopgood 2006, 215-216).

In this window of intensity, for some rights resonates deeply as an article of faith, and as affirmation of belonging. Akin to conversion, this transformation is often a powerful shift from a discourse emphasising suffering, to one where the common tenet is no longer a shared experience of vulnerability and exclusion, but a shared membership in the human race which

brings with it certain entitlements. This ‘broad church’ also allows for the meaningful and passionate involvement for those who cannot draw, or cannot draw as directly on experiences of suffering, because as humans they already belong to ‘humanity’ (or, on a smaller scale as citizens or the nation) and can advocate as members of that group.

7.2.2.3 Origin and Sustenance of Rights

All organisations had encountered rights language, though the depth and setting of their exposure to it varied, as did the support for their affiliation over time. The origin of exposure to rights language varied among those who used rights as a dominant frame. With BONELA, the source of rights was international, with international discourse prompting a UNDP Project Support Document which outlined the formation of BONELA. With TAC rights were local in origin, making new use of a dominant local discourse in the post-apartheid period drawing on both this historic language of struggle as well as its embodiment through the new South African Constitution. In ARASA’s case the origin was regional, reflecting the interest of several regional activists.

In each of these different settings however, founders and those in leadership roles held a high level of commitment to the rights frame. In one case, TAC, the domestic context served as a supportive factor to this popular discourse. These three groups also, to varying degrees, had institutionalised support for the frame, through its inclusion in organisational objectives. The groups also became well-known for this emphasis which served as a feedback loop in recruiting and sustaining this approach. In each case also, even where the discourse was not contextually dominant, the groups were able to find local resonance. Funders supported this approach, either directly (as rights-oriented groups themselves), or simply by funding the organisation.

While reflecting very different paths as noted in the table below, these three groups each illustrate exposure at the level of organisational founding and leadership, and support through champions (people highly dedicated to the rights frame), institutionalisation (development of rights culture, and codification in organisational objectives), funding and resonance. In each case these groups also saw it as important to tell others about rights, which reinforced their mandate and served to recruit likeminded individuals.

Table 12: Factors Sustaining Rights Discourse

<p>BONELA International discourse → UNDP PSD → BONELA formation → leadership → organisational culture → niche (reinforcing organisational culture) → linked to local norms</p> <p>Sustaining factors: linkage to local norms, organisational culture, funding, early leadership sought out supportive international connections</p> <p>ARASA Regional Activists, discourse in the region, influenced by South Africa and international discourse → international meeting → partnership → leadership → education (building partnership and bringing rights to new audiences)</p> <p>Sustaining Factors: Still has original director</p> <p>TAC Local discourse (Broad spectrum support, domestic coalitions, constitution)→ leadership → education → membership (becoming leadership)→ rights claiming (leading to increased faith in the frame)</p> <p>Sustaining Factors: linkages to local discourse, education of membership, successful rights claiming</p>

While the origin of rights is not as clear among groups who make less use of this frame, among several groups in the mixed category (TASO, NACWOLA) it appeared to be international exposure⁵¹⁰ for one or more people at the level of leadership. This was also the case with Kuru, while WUAAG appeared to have both individual domestic exposure (through the law), and international exposure (through donors) but neither of these perspectives, particularly the international, appeared to have taken hold at an organisational level. The origin of rights with

⁵¹⁰Exposure to the frame either occurring outside of the country, or being brought into the country from an international source.

SAfAIDS (rights mixed) and NAP+ (rights limited) was unclear, but seemed likely to be regional in the case of SAfAIDS.

In comparison with the rights dominant groups, groups in the other two categories, while all having been exposed to rights, tend to have erratic exposure, often to a limited number of people in the organisation, where the concept was not propagated and the roots did not (or have not yet) taken hold on a systematic organisational level. These groups also did not tend to have strong rights advocates or ‘rights champions.’ Among the rights mixed group, TASO had early exposure to rights at the level of an organisational founder, and tends to have a level of commitment to rights among founding employees. While rights appear in objectives, this commitment is not central, nor does it have an internal champion. As such, perspectives within the organisation remain diverse, with some seeing rights as central, and others viewing them as peripheral. Of the three rights mixed groups, NACWOLA is the closest to having the characteristics of a rights dominant group and, it is possible, that over time it may develop a stronger rights orientation and internal culture. At the time of research it appeared to demonstrate a shift between the more support based organisation and the rights-based advocacy groups. The group has had international exposure of several forms, including external assistance with campaigns from rights-oriented groups elsewhere in Africa and the world, and, at the time of interviews had new leadership with a demonstrated interest in rights. The group also initiated a new area of rights-based work, based on the influence of an international staff member, and has had two people in leadership positions come in who had a favourable approach to rights. At the local level, there is potential support for this shift through domestic coalitions which are rights oriented. Among groups with limited use of rights, sources of support are limited, and limited to

specific individuals. In the case of Kuru, while leadership has knowledge of rights, there has been a choice not to use this frame, due to lack of local resonance and traction.

7.3 Comparing Across Countries and Regions

In examining organisational identification and structure, understanding of human rights and origin and sustenance of rights, this chapter identified several key themes linking organisational structure and focus with conceptual understandings and leadership. These factors, however, do not operate in a void and are affected by the context in which both organisations and individuals find themselves situated. Context is clearly critical, and physical location, with its associated cultural, political and historical linkages, plays an important role in influencing how civil society operates, and advocates on HIV. This section conducts a brief overview of the four countries studied, and of the Southern African region, situating and comparing the organisations studied according to geographic location, sequencing them roughly from most to least rights-oriented.

7.3.1 South Africa

7.3.1.1 Case: TAC

South Africa is globally known for its vibrant activism borne of the anti-apartheid struggle. With one of the world's newest constitutions and one constructed with citizen involvement, the Constitution is invoked as a participatory and living document. Protests, marches, strikes and vocal and confrontational methods of advocacy are common and well-accepted. TAC has many features which link it to the South African context. Its rights emphasis and activist techniques draw directly on the anti-apartheid struggles, borrowing slogans and protest song melodies and repurposing them for HIV. Its structure, entailing district offices and community-based committees as well as a complex democratic process, reflects organising patterns of the African

National Congress. At a national level, TAC was not described by members as standing out in comparison with other NGOs due to its rights focus. While at the time of TAC's formation "there were very few organisations with the political skill and inclination to advocate for the rights of people living with HIV," (TAC 2009c, 4) there are currently at least 25 other advocacy organisations in South Africa listing HIV and human rights as their area of work.⁵¹¹ Rights discourse is a common vernacular, employed in multiple contexts and is now widespread in the HIV sector, and is the dominant language of advocacy. As such, while unique in many ways, in its use of law, and ability to mobilise large numbers and people and combine treatment literacy with rights education and action, TAC is a clear product of its environment, reflecting a new configuration of domestic themes and issues.

7.3.2 Botswana

7.3.2.1 Cases: BONELA and Kuru

While in South Africa being anti-establishment has historically-based legitimacy, in neighbouring Botswana being agreeable is heavily valued. As a country with a small and sparse population, Botswana is a place where most interactions are personal and with actors that individuals would expect to have repeated interactions. Consensus and consultation are strong themes, and it is customary for all parties with a stake on a particular issue to be invited to sit at the table, even if they hold opposing views (Maundeni 2004b, 219). Marches, protests and strikes are relatively unusual and confrontation and shaming, common activism tactics in many other jurisdictions, are not well regarded in Botswana (Maundeni 2004b, 219), with one

⁵¹¹Out of a total of 311 advocacy organisations online at <http://www.prodเดอร์.org.za/> (which bills itself as "South Africa's most comprehensive directory of NGOs and development organisations"), 25 were found to be local and non-profit and include reference to both human rights (the terms of phrases "right to" "rights" or "human rights") and HIV/AIDS in their description of activities, objectives, areas of work, or target groups.

respondent noting “people react very badly to the more overt forms of activism.”⁵¹² Human rights discourse is not unheard of but does not tend to be a dominant discourse, and is less likely to be drawn upon when negotiating sensitive topics.

In this consensual context, BONELA both reflects and contrasts with its environment. Defining itself as rights-based, the organisation is slightly less likely to rely on this language when campaigning on sensitive issues relating to sexual orientation. The group has also reflects Levitt and Merry’s concept of vernacularisation (Levitt and Merry 2009, 441-461), over time making increased making linkages in training and internal documents made links between human rights and the local concept of *botho*.⁵¹³ This understanding is also reflected in the manner in which people spoke about human rights – as a collective, a point of commonality and of union, of human need and experience, as opposed to an individual claim against an actor. *Botho* was also used as way of grounding the concept locally, and arguing against claims that rights are a foreign concept or imposition.

Although located in the same country, Kuru and BONELA exist in somewhat differing contexts. While BONELA is in the capital Gaborone, a city of some 200,000 people predominantly of the dominant ethnic group,⁵¹⁴ Kuru’s health program is run out of an unofficial settlement of 1500 people in the western Kalahari among the San indigenous people. Domestically isolated, and working with a marginalised population, Kuru chooses not to rely on rights, in part because of their lack of resonance with their constituency, but also due to

⁵¹² Author’s interview, Employee, International NGO, 2 July 2010, Gaborone, Botswana.

⁵¹³ Botho (known as ubuntu in zulu) is an African concept sometimes translated as “I am because we are” and expresses reciprocal humanity, whereby each person in recognising the other as human, also makes themselves human.

⁵¹⁴ Setswana-speaking peoples of the major tribes.

unproductive associations of rights with international activism on the part of the San people which was not well received domestically. Kuru makes a concerted effort to ground their approaches in the community in which they work and to build a constructive relationship with government that will enable consistent and appropriate access to relevant health care services for the populations they serve. Although BONELA and Kuru are very different organisations, the importance of local relevance, and the emphasis on consultation and consensus appear in both cases.

7.3.3 Southern African Regional

7.3.3.1 Cases: ARASA and SAfAIDS

As a region, Southern Africa is diverse, but also holds common influences and populations. Ethnic and language groups cross borders, the region is united through trade agreements and a regional organisation and is influenced by the long political and economic shadow of South Africa. The region is host to a number of regional NGOs, usually located in South Africa, but also occasionally Zimbabwe. ARASA and SAfAIDS are both members of the Regional Association of AIDS NGOs (RAANGO), and both reflect elements of regional influences. ARASA, which has a direct and overt rights emphasis is more tightly tied to a network of activists, many from South Africa, with a clear rights orientation. While headquartered in Windhoek, the group has a growing presence in South Africa, and although this country is not one in which they conduct much advocacy,⁵¹⁵ the groups' location there and recruitment from there have an impact on its approach. ARASA, however, remains a partnership and, as it has grown has increasingly diverse membership. SAfAIDS maintains a larger number of offices than

⁵¹⁵As ARASA views South Africa as having sufficient capacity.

ARASA, and their headquarters have moved between Harare, Zimbabwe and Pretoria, South Africa. While drawing on rights in some work, this group relies at least equally on development, and placed heavy emphasis on dialogue. These two groups stood out from the other organisations in this study through their heavy emphasis on process. Perhaps reflecting the practical realities of working across a region and amid diverse cultures, both organisations emphasised listening, dialogue and learning from others.

7.3.4 Uganda

7.3.4.1 Cases: NACWOLA and TASO

In Uganda, rights language is not unfamiliar in HIV advocacy but is customarily used in combinations with other frames including development and gender. Civil society groups consulted reflected a shift over time from a public health approach to one emphasising development and human rights, with the shift attributed to the progression of the pandemic and the availability of anti-retrovirals. Groups also noted a shared experience of high death rates from the earlier years of the pandemic, and the sense of a having collectively survived a crisis (while many others did not). They expressed craving a more caring response than the earlier fear-oriented warnings that “AIDS kills.”

These themes were reflected in the two Ugandan cases, both of whom made reference to rights among other frames. NACWOLA, a women’s organisation, demonstrated a shift from a sympathy based approach (within an overarching gender frame) to one increasingly incorporating rights, in conjunction with other approaches. TASO, one of the oldest HIV organisations, conducts advocacy as well as extensive service provision and was perceived by some respondents, particularly founding members, to draw on rights in a stigma and

discrimination context. The group experienced a significant shift over time, from an emphasis on ‘dying with dignity’ to one highlighting living with the virus. The two groups both found work on gender to be particularly challenging and important, and to be an area in which reference to rights was both most likely and most controversial.

7.3.5 Ghana

7.3.5.1 Cases: NAP+ and WUAAG

Ghana has the lowest prevalence rate of the countries and regions studied, being the sole location without a generalised epidemic. Advocacy and messaging oriented towards general education around HIV were more common than in the other jurisdictions and HIV was a lower profile issue. Generally there was less ‘activist’ inclination in Ghana among HIV groups with more emphasis placed on dialogue and need and education as advocacy strategies.

Among the Ghanaian groups studied, NAP+ and WUAAG, there tended to be a legalistic understanding of rights, with the concept often equated to laws, legal remedies, or to a government body called the Commission on Human Rights and Administrative Justice (CHRAJ). For some, the explanation of using human rights as a campaign tool was not one of choice but simply of what ‘were and were not rights’ saying that if it was not in the law, it was not a right, and you could request but not demand. Unsurprisingly, the enforceability of rights was frequently mentioned. Likely because of the legalistic understanding of rights, several people indicated that rights were not useful in dealing with communities because they did not have high levels of education and were not familiar with them. One of the main campaigns underway is for free anti-retroviral drugs. While in some contexts this would easily be framed as a right (to health, to accessible treatment, or to non-discrimination in comparison with other

medication and health conditions) here the dominant argument is need (ie, we need drugs and not everyone can afford them). Interestingly also, many groups worked on stigma and discrimination but would often not view it in rights terms. Instead, need and sympathy were highlighted in order to impart the personal experiences and impact of particular policies on a person's life.

7.3.6 Geographic Trends

Comparing across countries and contexts illustrates some clear trends in both language and methods. While human rights and confrontational activist strategies are common and historically grounded in South Africa, and, partly as a result, have some level of familiarity throughout Southern Africa, they are less dominant elsewhere. There tended to be a moderate level of rights exposure in Uganda, and rights were lower profile in Ghana. With some exceptions, the groups analysed usually followed roughly the same trajectory, with groups located in, or more closely connected to Southern Africa more likely to rely on rights. There were several indications of cross-regional connections between Southern and Eastern Africa, including two organisations that brought together groups in the two regions. In Ghana, there was some indication of training, connection and learning from East Africa, and particularly Uganda. Table 15 illustrates the spectrum of rights use by country and region examined in this study.

Table 13: Rights Orientation by Geographic Location

Country/Region	Rights Dominant	Rights Mixed	Rights Limited
South Africa	TAC		
Botswana	BONELA		Kuru
Southern Africa	ARASA	SAFAIDS	
Uganda		NACWOLA, TASO	
Ghana			NAP+, WUAAG

7.4 Concluding Across Categories, Themes and Countries

The three methods of comparison illuminate common themes. Comparing across categories indicates that at the intra-organisational level, leadership, initial mandate and belief in rights play a critical role among the rights dominant category, while personal experiences and constituency

play a greater role in those with a mixed or limited use of rights. Rights dominant groups tend to hold organisational niches based on frame or technique rather than constituency, and while there were common donors across categories rights dominant groups have more rights oriented donors and fewer domestic donors. The groups also illustrate different beliefs about impact, with an association of rights and strength considered a key catalyst among rights dominant groups, process viewed as most important among rights mixed organisations, and highlighted need or vulnerability seen as pivotal among rights limited groups. When comparing the relative weight of these factors, internal factors appear to be more important in the rights dominant group where frame is often justified on the basis of belief. The rights mixed group illustrates the impact of external interactions on frame. The rights limited group is primarily influenced by its constituency with respect to frame.

When comparing across themes and variables, cross-cutting themes emerge, some of which reinforce the earlier comparison across categories. Rights dominant groups are more likely to have issue-based rather than constituency-based organisational identification, tend to be secretariat-based rather than membership-based organisations and usually hold an expansive rather than topical or limited legal perspective of human rights. While origins of rights are diverse across and within categories of groups, exposure at the level of leadership is important, as is the ability to develop support for the frame through personnel and funding.

Comparing across countries and regions indicates that there are particular geographic trends with rights dominant groups tending to occur in Southern Africa. South Africa in particular has a dominant rights discourse affecting both national and regional groups. In Uganda, rights are a common but not dominant discourse often used in concert with other frames, while in Ghana,

among groups studied rights are peripheral at best and viewed as having limited applicability. There is also evidence of a regional flow in information, whereby rights-based approaches and ideas often flow from Southern Africa, particularly South Africa, groups in Uganda in several instances have connections with groups in South Africa, and groups in Ghana have had connections or undertaken training in Uganda. It is important to note, that while these geographic trends are significant, this is not a comprehensive study of the entire NGO sector in each location, nor of every group working on HIV.

Chapter 8: Conclusions

Building on the comparative analysis conducted in the last chapter, this chapter seeks to: (1) distill the project's findings on rights-choosing among HIV advocacy organisations, (2) identify contributions to the literature and implications of the findings, (3) propose areas for future research. In part 8.1, I lay out a theoretical explanation of the decision to use the rights frame. Mirroring the theory chapter, part 8.2 identifies contributions to the literature in four areas: human rights, health, civil society and framing concluding with a discussion of implications. Finally, part 8.3 explores avenues for theory testing as well additional areas of research to examine the potential scope of this explanation.

8.1 Towards a Theory of Choosing Rights

Choosing rights is a process that occurs at multiple levels, and a choice that is made repeatedly over time with reinforcing consequences. The selection and sustenance of a human rights frame is: (1) an organisational choice which requires particular actors and structures and (2) an individual choice directed by particular beliefs about the concept that is (3) influenced by the context in which it is located.

To distill a complex story into a single word, based on the cases studied, the 'human' plays a critical role in organisations' adoption of the human rights frame, particularly in settings where the rights discourse is peripheral. Champions, in the forms of early leaders with a strong level of personal dedication to human rights and to the explicit language of human rights play a critical role in the ongoing use of the frame. The ability of these champions to be influential, however, depends on specific structural factors. Groups that are smaller and

primarily secretariat-based allow greater opportunity for influential rights-based leaders to create a rights-oriented organisational culture through regular interaction with and recruitment of staff who hold, or will acquire a rights orientation.

To return to the title of this dissertation, as an organisational frame rights are indeed a choice. They are not an inevitability or a donor-directed process. Despite connections to legal enforceability, and the existence of legal aid clinics and litigation initiatives, respondents did not highlight ties to legal accountability (Yamin 2008, Gloppen 2008, Forman 2008) as the reason for choosing rights. The choice of rights reflects belief among the leadership in the concept. The belief in rights does not always jive domestically, nor is it a language that is thought to always be successful. Even among rights dominant groups rights was not the prominent theme in every campaign, with the ‘fit’ of the frame of specific campaigns depending more on social and political sensitivities than the resonance of rights with the specific issue being addressed. Issues which had a strong logical connection to rights, such as prisoner’s access to condoms in Botswana, were not always articulated as rights in settings where cultural or political attitudes toward that topic, or toward the affected group were negative or controversial. Conversely topics with more tangential rights connections, such as TAC’s work on funding health care infrastructure, were sometimes articulated in rights language in contexts where rights was a popular domestic discourse.

At an individual level, a key theme emerging with reference to rights selection is a strong belief in the concept’s empowering impact on organisations’ members and constituencies. Rights are experienced as powerful forces able to transform the identities of individuals, including advocates themselves and the constituencies they seek to influence. Rights are

understood as entailing a shift in conceptions of the self and of entitlements with reference to the state and others. This shift is a necessary precondition for individuals to claim their rights, with particular but not exclusive reference to the health care system. Rights transform people from recipients to participants.

Once “empowered to know what [they] are entitled to” people are able to “claim the rights wherever [they] go” including requesting appropriate care and medication at health clinics and negotiating safe sex.⁵¹⁶ In contrast with other frames emphasising vulnerability which allow for requests and demonstrated need, rights are seen as facilitating demands which, in conjunction with knowledge (about medication, rights, laws), serve as a catalyst for active rather than passive participation in healthcare and ownership of one’s health. In the words of one respondent, once empowered through rights, “you are responsible for your own health and responsible for other people’s health.”⁵¹⁷ As a result of the transformation from recipient to participant individuals are able to claim health care and to question health care professionals when they disagree with treatment recommendations or require clarification. Considering the often stark power imbalance and educational inequities between those seeking care and those providing it, questioning is an act that asserts strength and challenges customary practices and hierarchies. This assertion is the activation of what Yamin terms the “subversive potential” of rights which, as she describes it, transforms both the violated and the violators, changing power dynamics in the process (Yamin 2008, 13).

⁵¹⁶ Author’s interview, Anna Mmolai-Chalmers, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 29 June 2010, Gaborone, Botswana.

⁵¹⁷ Author’s interview, Anna Mmolai-Chalmers, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 29 June 2010, Gaborone, Botswana.

‘True believers,’ that is, respondents who referred to rights in a non-strategic manner, exhibiting personal conviction and belief in the concept, were common among rights dominant organisations. These individuals tended to speak, unprompted, at great length about the concept, and did not tie their support for the concept to government or donor preferences. Passionate commentary on human rights was common including descriptions of human rights as “the reason why we exist” and “inherent to existence as a human being.”⁵¹⁸ Indeed, the use of rights was usually explained through an elaboration of characteristics of the concept, where it was portrayed as inherently valuable and with a strong impact at the individual level. One respondent, for example, expressed the view that the use of rights was a good in and of itself and should not be justified by health outcomes as doing so reduces human rights to a utilitarian function.

The context in which organisations and individuals are located also has an impact. Rights language is more common among groups in Southern Africa where the discourse is generally more popular and has greater resonance. Nonetheless, even in this region there is variation in the form and use of rights, particularly between settings where rights are a dominant domestic discourse and those where it is viewed as an adversarial language with outside origins. In contexts such as Botswana, where the language of rights is not a domestically common discourse, greater care is taken to nest rights in local cultural terminology (for example, BONELA’s reference to *botho*). In such settings also, rights are expressed as a

⁵¹⁸ Author’s interview, Program Manager, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 28 June 2010, Gaborone, Botswana.

language that brings people together and emphasises commonality rather than difference. In contrast, in neighbouring South Africa, where the language of rights is common and is understood as local, direct and confrontational language is more common, and rights are more often articulated as a claim on a duty bearer (usually the state).

The civil society context also has a strong influence on the extent to which groups choose rights. Civil society organisations are more likely to take on issue-based identities such as rights where constituency-based groups already exist and represent those groups well. In this context issue-based groups are able to occupy an available space; to identify, as many respondents put it, “a gap”⁵¹⁹ in the dialogue or response and to locate themselves within that niche. In areas where rights discourse is not locally dominant, the rights niche is available and easily and eagerly occupied by rights champions who often encounter rights in regional and international contexts and who counter their domestic isolation with regional and international contacts who provide a lifeline of ideas, networking and interaction. Finally, funding is available for this type of work. As the niche becomes more established and better recognised, particularly in more isolated settings, donors and recipients become better able to identify each other and to target funding applications and projects. Throughout this process, the depth and understanding of rights tends to vernacularise over time, increasingly reflecting local concepts and processes. As such, groups become stronger, and serve to feed these local concepts and methods back to their international partners.

⁵¹⁹ Author’s interview, Uyapo Ndadi, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 27 June 2010, Gaborone, Botswana.

Rights are a choice, and a not entirely predictable choice, particularly in contexts where the terminology is viewed as foreign and confrontational. And yet, an often small group of true believers in this concept are able to advocate under this banner, gaining currency and occupying a niche over time. Viewing rights as an empowering language of inclusion and belonging not ‘us against them’ but ‘we are also part of ‘us,’’ this relatively small number of committed individuals has been able to gather rights-oriented personnel and create a rights based organisational culture. In doing so, these organisations focus on sharing the concept with “people who enforce [the right to health] themselves” (Grover 2009, 1-3).

8.2 Literature and Implications

At the outset this project was situated in relation to four real world topics and areas of study: (1) Human Rights, (2) Health, (3) Civil Society and, (4) Framing. In this section I examine potential contributions from this project in each of these areas concluding with a brief overview of the implications of research findings.

8.2.1 Human Rights

This project contributes to thinking on human rights in three areas: (1) generational divides, (2) human rights and law, and (3) local conceptions of human rights. The findings suggest that activists working on HIV are actively questioning divides between first and second generation rights, fighting for them in tandem and querying the positive/negative distinction. They also increasingly share techniques, language and perspectives with more traditional civil and political rights groups and should be studied alongside such organisations. The field of human rights remains predominantly legal, this project indicates that there is a need for further social science research on human rights contributing to the field of human rights in

addition to contributing to the field of social movements and civil society. Such research could further explore human rights as a tool of activism and as an individually rather than state-oriented frame. Finally, this project suggests that there are interesting locally-grounded conceptions of human rights on the African continent that may manifest themselves and be invoked in ways that are distinct from their northern or western counterparts.

8.2.1.1 Generational Divides

Despite the Vienna Declaration's pronouncement of "indivisibility" of first and second generation rights, the divide remains real, reflected by their codification in two different covenants (the ICCPR and ICESCR), differential language of enforcement, and ongoing disciplinary divides with respect to their study. The term 'human rights,' when used without qualification, is usually assumed to mean civil and political rights, and it is chiefly these rights that are examined by those who study rights (see for example: Risse, Ropp, and Sikkink 1999). If such rights are usually studied within politics and law, economic, social and cultural rights more often reside in development studies.

Activism on HIV/AIDS brings together the two generations of rights, finding it difficult to separate discrimination from health care, or violence from access to education or housing. Studying health activists as human rights activists allows for an examination and comparison with activists in more 'traditional' human rights fields. In comparison with such groups, the activists and organisations in this study were more likely to use rights in direct rights claiming with service providers and citizens. They were also able to question the positive/negative or passive/active rights distinction, viewing passive acts as active

violations, stating for example that “just like you have the right to not be killed by someone in a violent action, you also have the right not to be passively killed by a government because they refuse to invest in your health.”⁵²⁰ In a striking example of this equation is TAC’s poster featuring two children killed by their respective governments, Hector Pieterse who was shot by the apartheid government during the Soweto uprising, and Nkosi Johnson who died due to lack of ARVs. Such assertions shifted the discourse from a passive ‘you are allowing us to die’ to the active assertion ‘you are killing us.’ This equation is an important one, both for theorists who attempt to classify and separate varieties of rights, but also for those who study rights advocacy and rights activists. On both fronts, this study suggests that an inclusive approach (examining positive and negative rights together, and activism on both generations of rights) is preferable and likely to hold more explanatory power. This project suggests that HIV activists, and possibly health activists in some other areas, increasingly share methods and perspectives with groups working on more traditional rights topics.

8.2.1.2 Human Rights and Law

Despite significant progress in diversifying the field, human rights remains a field of study that is predominantly studied and justified in relation to law at both national and international levels. As Freeman notes,

Worldwide the understanding and practice of human rights are strongly dominated by legal thinking, practices and institutions. However, in recent years there has been a growing recognition that this dominance has been excessive, and has inhibited both our knowledge of what human rights are and of how they can most effectively be realised (Freeman 2012, 3).

⁵²⁰ Author’s interview, Employee 1, AIDS and Rights Alliance for Southern Africa (ARASA), 8 August 2010, Cape Town, Western Cape, South Africa.

Indicators such as the ratification of treaties or passing of laws, however, are usually quite remote from human experience. As Freeman argues with reference to large-N quantitative studies (which often use such indicators as their basis) such research can “seem to take the ‘human’ out of human rights,” as “[t]hey do not tell us what human rights mean for those whose rights they are, nor how human rights may be understood differently in different social contexts” (Freeman 2012, 8). The idea of a rights culture emerging from legal creations, in particular Western-initiated UN covenants, has been critiqued as “a peculiar culture in the sense that it is declared rather than lived, and that it is future-oriented rather than based in tradition” (Hastrup 2003, 16-17). In drawing on methods based in the social sciences rather than law, and interviews and observations rather than ratifications, this study has sought to understand human rights as a tool chosen by organisations rather than a declared commitment by states, viewing it as a conceptual frame that is pieced together through interaction with local and international actors. In doing so it has illuminated several findings that would not be accessible to researchers relying more legally-oriented measures or methods.

In its emphasis on recourse, law at the national level draws much of its material from cases of unsuccessful or disputed rights claiming that have been elevated to the courts and sometimes result in important and influential precedents. This macro-level record of failures and disputes sometimes translated into legal successes does not capture the micro-level victories that occur between people living with HIV and their health care providers, neighbours, employers or partners. Such processes include negotiations between people living with HIV and these parties, as well as interactions that occur between individuals and civil society

groups, which can result in changing attitudes and beliefs that influence behaviour. These grassroots interactions are, in some respects, the mechanisms of how human rights do or do not work on a day to day basis within communities. This study indicated that the use of rights language by advocacy groups is believed by those who use it to result in such individual-level rights claiming particularly in the health care sector. This finding indicates that the power of rights may exist partly independent of legal protections, and, more certainly, that its impact, particularly its positive impact will not be adequately reflected in legal indicators such as court cases.

The study of rights generally, and a law-based approach more specifically, can focus on formal legal outcomes to such an extent that it often marginalises or overlooks process. Conversely, advocacy is inherently process-oriented, involving education, persuasion, relationship-building, and often long-term engagement. The role of process was emphasised by several of the groups within this study (in the rights dominant and rights mixed groups). Within these organisations process was seen as more than a means to an end, but instead as an act of capacity-building, and in some cases a goal in and of itself. Some interviewees viewed their participatory processes as demonstrating the core characteristic of a rights-based approach.

Even outside of the discipline of law, legal measures and structures influence the way in which human rights are studied. The study of international human rights tends to focus on the behaviour of the state viewing it as the actor that can violate, respect or promote the rights of its citizens. The state is usually placed at the centre, even where there is strong

acknowledgement of the importance of non-state actors. Simmons, for example, highlights the importance of civil society in promoting treaty ratification and in monitoring its enforcement, but still views the state as the primary actor empowered to respect or violate rights (Simmons 2009). In her work on sexual politics, Brysk emphasises the difficulty of working on rights violations committed by private actors asking how the state might better respond to such abuses (Brysk 2013).

In simple terms, much of the human rights literature is focused on a very important state-centred question: “How can we improve state respect for human rights?” While not divorced from this important question, this dissertation places far more emphasis on individual behaviour, and on individual rights claiming. Among other findings, this project highlights the impact of rights on the interaction between two individuals, one seeking care and the other providing it. This project finds the primary impact of rights is on those claiming them rather than on those providing them, responding in part to Brysk’s call that:

the next generation of human rights research should consider how to govern abusers whose hearts and minds cannot be changed, by empowering victim, bystanders, and government who can (Brysk 2013, 274).

In contrast with an emphasis on high-level government decisions, this dissertation highlights the importance of rights in day to day interactions in health facilities in securing health rights, rights that remain subordinate to civil and political rights in the human rights literature. A nurse employed in a public clinic is seldom depicted as the “face” of an oppressive regime in human rights literature, nor is ineffectual health care usually depicted as a violation. A health clinic is seldom depicted as a battleground for human rights, and the most important human rights victory is rarely reported to be an internal shift in self-identification and behaviour. In

exploring rights as a tool of empowerment in the field of health, this project begins and ends in very different locations than most rights research. In doing so, it contributes to a widening of the scope of what constitutes human rights research and how we might understand the impact of human rights.

8.2.1.3 Local Conceptions of Human Rights

The literature tells us that the appeal of rights as a frame may lie in rights' conceptual "fluid[ity] and open[ness]," or call to international standards (Levitt and Merry 2009, 457-459). The study of international and local dimensions of human rights often takes the premise that the origin is international, and that the spread of human rights is a manifestation of globalisation, whereby ideas become diffused into new and unusual settings. While this research does certainly indicate the spread and diffusion of ideas across both geography and topics, the findings indicate that rights language originates from and travels in several directions. On the African continent, rights originate not only from the north (primarily Europe), but also from the south. South Africa is a strong influence, particularly in Southern Africa, but also throughout the continent, bringing rights language through regional interaction and networks.

In line with work by Levitt and Merry, this project suggests that as rights travel they are modified and "vernacularized," becoming increasingly grounded in existing and evolving local concepts, norms, practices and histories (Levitt and Merry 2009, 441-461). The frame is not simply received, but molded with new hands and to new purposes. As such, rights become a localised concept and are linked in with local histories, for example, in the case of South Africa linking a rights-based struggle on HIV to previous race-based rights struggles.

They are also linked to local concepts, as evidenced by BONELA's increasing use of the local *botho* concept as an indigenous reference point / translation for rights. Local conceptions and understandings of rights are often lost in the polarised debate over human rights as a series of universal global norms, or as relative locally-bounded concepts. This research, particularly with reference to *botho* / *ubuntu* suggests a form of localisation that involves both reimagining human rights and the local concept.

8.2.2 Health

There is limited interaction between those who study health (located primarily in the health sciences) and those who study civil society (located primarily in the social sciences). While Davies argues that “those who study world politics need... to understand that health is a political issue that impacts at the local, national and global levels” (Davies 2010), so too could those in health benefit from linking social science questions to their important quest for improved health outcomes. This research suggests important actual and potential findings at the crossroads of political science and health, indicating that further work at this complex intersection would be fruitful in addressing key questions in both disciplines.

Public health and medicine seek optimal health outcomes and aim to structure medical and behavioural interventions that will achieve these goals at both population and individual levels. The problems related to HIV are numerous and are grounded in social and economic as well as medical factors. Widespread problems include: people not testing or accessing care until they are quite ill, lack of access to and use of methods of prevention, social stigma against bottle-feeding infants and lack of access to formula, lack of adherence to medication, and general difficulties in accessing treatment and care.

This research indicates that rights dominant organisations believe that the use of rights in advocacy actually increases the ability of people living with HIV to access health care services, and to advocate for their health in that context. This finding alone is interesting when studying motivations for frame selection and indicates a strong belief in the impact and influence of rights discourse on individual behaviour. If, however, this belief in impact can be substantiated it could also hold very important findings for health researchers. Accessing health care services and being an informed self-advocate are both factors that improve health outcomes. Therefore, if the beliefs of rights users are accurate, choosing rights may have a measurable impact on health outcomes.

The linkage between activism and health outcomes has, to date, only been made in a tentative fashion through the use of the framework of social determinants of health. The Commission on the Social Determinants of Health has indicated that part of the response needed is “[s]upport for civil society” and “for people across society to ... reinvest in the value of collective action” (Commission on Social Determinants of Health 2008, 2). Mark Heywood, a South African activist, in reflecting on this statement has argued that “[w]e need to see the level of activism by civil society as a key social determinant of health,” noting that such a fight must be “not in the abstract” but “for the specific goods, institutions, demands and resources that will realise the right to health” (Heywood 2011,1).

Heywood’s pronouncement is very much a departure from conventional understandings of social determinants of health. Social determinants of health are usually conceived of as factors such as poverty or gender that render particular populations vulnerable to disease and injury. These determinants predominantly portray the vulnerable individual as being acted

upon by these factors, resulting in negative health outcomes. Heywood's argument suggests a social determinant defined by unity, strength and mobilisation, indicating a movement away from a traditional emphasis on vulnerability, instead viewing individuals as agents seeking and securing their own health. These factors highlight resiliency, response and agency rather than vulnerability, and emphasise connection and mass reactions rather than isolated individual experiences. While Heywood suggests that the level of activism may be a key determinant, this study suggests that the frame of activism may be the critical feature, indicating that the language of advocacy and the manner in which it affects individual behaviour could be linked to improved health outcomes.

8.2.3 Civil Society

Studies of internationally-linked civil society organisations usually begin at the 'international' end and focus on the diffusion of ideas and practices from that end. In contrast, this study began at the 'local' end, examining African-based groups, each with some level of international connection. While international connections proved important in many ways, including in access to funding, recipient groups are very much actors in this scenario, picking and choosing both methods, topics and, in some cases, funders.

Power dynamics between donors and the groups they fund are not as clear as the money might suggest. While funding is essential, the shift to project-based funding means that donors tend not to hold influence over an entire organisation's frame. Also, successful groups draw donors by their success, as donors want to work with groups receiving praise and recognition. So, while some groups may feel they are at a donor's beck and call, others have

significant leeway in selecting projects and funders, even refusing money from particular sources on principle.

Civil society groups are often understood in two ways, those that are local and embedded and resonate with the communities from which they come, and those that are dissonant and are funded or otherwise directed from foreign influences (see Orvis 2001, Lewis 2002). This project identifies a third group, those that are locally grounded but ‘out of context’, holding views and approaches that are not locally dominant. This unusual position allows such groups, where they are successful, to utilise that sparsely-occupied niche as a strength in advocacy and organisational identity. It also allows for perhaps greater flexibility in conceptualising non-dominant frames such as human rights, in the absence of local competing versions. This position introduces two competing tensions: the strength and opportunity of having a different approach, and the isolation and possible accusations of holding foreign ideas or being beholden to foreign interests. These two pulls have, in some instances, resulted in innovative re-thinking of concepts such as human rights and efforts to ground these concepts in local norms, beliefs and practices. This illustrates a confluence of “vernacularization” (Levitt and Merry 2009, see also Acharya 2004 on “localization”) and organisational and bureaucratic factors (Cooley and Ron 2002, Barnett and Finnemore 2004) in the manner in which organisations select, operationalise and optimise their use of frames in their local culture and civil society context.

The importance of organisational structure also highlights the relationship between civil society groups and their surroundings. This project found that, in the absence of a strong domestic rights discourse, centralised secretariat-based organisations with strong rights-

oriented leadership can sustain the rights frame. This finding has several implications. It means we are unlikely to see rights-based decentralised membership-based organisations in environments where rights are not a common language of advocacy. If an individual planned to start a rights oriented group in such an environment it would be most likely succeed in settings where: 1) other forms of representation already existed for the constituency the organisation would advocate for (i.e., support groups for people living with HIV); 2) there are not strong negative associations with rights; and 3) there are not negative associations with rights in association with the group of people the organisation would advocate for. In these contexts the founding leader holding a strong affinity for rights would need to start small, gathering a small number of people who hold or could acquire a rights orientation. This small office where everyone interacts regularly with leadership will serve as an incubator for the rights frame. Over time the group may become known for that frame, gathering others with a similar mindset and, developing and occupying an organisational niche relating to rights. Leadership appears critical in this process, as does a genuine belief in the value of the rights frame. As noted above, the need for centralisation where groups appear ‘out of context’ does not mean that such organisations are entirely divorced from their surroundings. Even while standing out for their use of rights, such groups draw on local practices and advocacy norms, and interpret, understand and explain human rights through a local lens, a concept that often becomes more “vernaculariz[ed]” (Levitt and Merry 2009) over time. If a group sought to eventually decentralise, based on these findings, I would expect that it would be necessary to first develop a strong rights-based culture in a single office, and then slowly over time develop field offices with leadership socialised in the head office and holding a strong rights orientation. In these regional offices it would be important

for the office to be a location for regular interaction rather than primarily providing field support.

8.2.4 Framing

The norms literature that examines framing tends to focus on three areas: (1) the characteristics of the frame; (2) the characteristics of the organisation and its fit with the frame; and (3) the characteristics of the context and the resonance of the frame. Each of these features is important. Obscured somewhat in these bigger-picture analyses is the role of the individual and the relationship between the frame and the individual.

The literature of civil society organisations and activism notes that material incentives and constraints play an important role in shaping NGO behaviour (Cooley and Ron 2002, 6). This body of literature also emphasises the importance of fit: with respect to the organisation, other groups (Bob 2007, 167-193; Carpenter 2007b, 663), and in relation to the issues and the audience, including adaptation of frames that come from without in order to better resonate in a local context (Levitt and Merry 446-449). Material incentives, in the form of funding and the availability of niches with respect to other organisations, are clearly important components of each group's existence including, in some cases, their founding. However, neither of these issues appears to be the critical factor in the ongoing decision among rights dominant groups to choose rights time and again. The idea of fit is important and involves the adapting of frames to suit local contexts (Levitt and Merry 2009, 446, 449), seeming to take place as a gradual iterative process rather than an immediate reformulation of new ideas.

What stands out, however, from this research is the importance of the relationship and fit of the rights frame with the individuals who use them, and their influence on the people who are affected by rights-based campaigns. As a frame, rights are also thought to hold “subversive potential” transforming both the violated and the violators, challenging and changing power dynamics in the process (Yamin 2008). Indeed, rights highlight the role of process (Gruskin and Daniels 2008, 1577). In contrast with many other frames, rights hold some direct ties to legal accountability (Yamin 2008, Gloppen 2008, Forman 2008) and also have a linguistic and conceptual link to moral ‘right’ (Forman 2008, 39). As an international language rights can be an effective rallying cry, assisting local groups in linking their struggles with groups beyond their borders (Bob 2007, 167-193).

The greatest benefit of rights, from the view of the groups making dominant use of them, is in line with Yamin’s analysis, highlighting a shift in power. Rights dominant groups view this terminology as holding transformative power and enabling members and constituents to claim their rights in practical day to day settings. Rights are seen as a frame which empowers those living with HIV to demand services owed to them, to make requests from a position of power and entitlement, rather than weakness and desperation. The legal connection, while varying in strength, exists among all rights dominant groups, with TAC in particular well-known for its legal victories. Despite this, legal accountability is not highlighted as a key reason for the use of rights. The organisations studied do not, with the possible exception of TAC in the unique South African context, emphasise the importance of rights as a tool of mobilisation.

At the outset of this study, my primary understanding of impact was the ability to influence government policy, law and procedure. I hypothesised, in part, that the rights frame might be popular because of its ability to resonate with decision makers and impact upon these processes. Responsiveness of government appears to be less central than anticipated, with the rights dominant groups studied understanding impact as a broad concept, and one occurring at many levels, with the chief impact of rights understood as being located at the individual level. At this level contact with rights is viewed as a transformative process changing the relationship between the individual and the state.

8.2.5 Implications

Having identified key contributions to the literature, I now turn to the broader question of the actual and potential implications of this research. First, this project indicates that human rights are powerful as more than legal tools. This research shows that rights-based advocacy is important and influential even where it does seek to or succeed in changing law or policy. This finding is important to human rights and advocacy research because it suggests the need to look for impact in new locations when assessing advocacy campaigns, particularly at the individual level. Implications of this finding extend to donor agencies and civil society advocacy groups who may need to re-think and re-articulate how they understand the impact of their activities, and how they measure and communicate impact. NGOs may, for example, need to develop new structures to evaluate advocacy if it is aimed at individual-level change.

Second, the implications of the individual-level impact of rights-based advocacy are potentially far reaching. While this study limited itself to exploring why civil society groups choose to employ rights, the belief in individual empowerment that fueled this choice merits

further research. If the empowering impact described by respondents within NGOs is similarly experienced by advocacy recipients, such advocacy may be responsible for a sea change in the way in which individuals, particularly vulnerable people living with HIV, interact with health services. Furthermore, the behavioural consequences of this empowerment, including more pro-active interaction with health providers, an increased likelihood to seek and insist on care, and a greater propensity to ask questions, may result in improved health outcomes. If rights-based advocacy does indeed lead to better health through higher rates of clinic attendance, medication awareness and adherence, for example, this would be very useful in informing health care spending, and in re-conceptualising rights-based advocacy as a health intervention.

Third, as noted earlier leadership and organisational structure are critical in frame choice and use. The impact of leadership in incubating and disseminating the rights frame even in settings of relative isolation suggests that individual belief and action are key areas of study. In practice, this finding has several implications. It suggests that individuals can and do hold significant influence and can create thriving rights-based groups even in locations where the discourse is not dominant. This finding also provides several suggestions, as discussed earlier, about the way in which a leader may choose to structure their organisation if they intend to conduct rights-based advocacy in a setting where rights are not domestically prominent, favouring a small centralised structure over one that is more diffuse.

Finally, this project's findings are important with respect to how we understand and study frames. This research indicates the importance of individual-level frame resonance both

among organisationally-based users of the rights frame and advocacy recipients. This differs from conceptions of frames that emphasise fit with organisations, topics or broad audiences. This project also suggests, as discussed earlier, that there is something qualitatively distinct about the rights frame and the strength of personal allegiance it can provoke. This strong personal attachment could mean that rights-based groups are less likely to change frames over time, another topic worth exploring further in future research.

8.3 Areas for Further Exploration

8.3.1 Theory Testing

As stated at the outset, this is a project of theory building rather than theory testing. As such, it inherently lays out areas for further exploration with respect to scope and applicability. It would be useful to examine the applicability of the propositions generated in this project in countries that are comparatively less prosperous than the ones studied, in countries that are less politically stable, and outside of Anglophone Africa. I would anticipate that the use of rights would be less prominent in areas where civil society has less freedom to operate, that the use of rights-based language around access to services may be less frequent in countries with very limited access to health care, and there may be different linguistic trends outside of the anglo-sphere. Research into such topics would indicate whether contextual factors of relative wealth, political stability and language hold any explanatory power or limit the applicability of the findings of this research. There may also be distinctive continental features in relations to human rights which shape the manner in which these theories are able to travel to other parts of the world. Further research in these areas will also enable more

conclusive isolation of variables that may offer alternative explanations, such as political institutions and political economy.

Beyond geography and context, it would also be useful to examine the applicability of this explanation to other forms of health advocacy. In several of the jurisdictions studied there is increasingly joint work, and joint advocacy on HIV and TB due to very high rates of co-infection. TB, a highly contagious but treatable condition, is a very different illness. TB is associated with poverty and overcrowded living conditions, but only indirectly through HIV to some of the socially stigmatised behaviours that led in part to the emergence of the rights frame in response to HIV. HIV is also sometimes joined programmatically with reproductive and sexual health, another area of health advocacy that would be useful to explore, and one in which there is already some evidence of the use of the rights frame. Another area for potential exploration is of the growing field of disability rights, to examine what overlaps or parallels may exist there.

The scope of these findings can also be further specified with reference to the groups of people (rather than the health conditions) by whom or on whose behalf rights claims are made. One theme that emerged from this research was the suggestion of a complicated relationship between marginalisation and the use rights language, where paradoxically, it appeared to make the frame sometimes more and sometimes less likely to be used, depending on the characteristics of the marginalised group. The links between marginalisation and HIV infection, and marginalisation and rights are often made. Indeed, some continue to echo, the words of health and human rights trailblazer Jonathan Mann's observation that "social marginalisation, discrimination and stigmatisation, in other words a lack of respect for human

rights and dignity [are themselves] a root cause[s] of the epidemic” (Mann as cited in: O'Connor 1995). However, the linkages between marginalisation and rights-based advocacy are unclear. This research could be particularly useful as such groups often have lower than average uptake of and access to health care services, and may be more likely to use civil society groups as their first port of call, particularly in relation to criminalised behaviours (such as same-sex sexual activity and sex work).

8.3.2 New Questions

As is often the case, each question answered reveals more to be asked. This project illustrated why groups choose rights, examining some groups who began and stayed rights oriented, and some who, over time, acquired a degree of rights orientation. It did not, however, examine why, how and whether groups ever move away from a rights dominant approach. This would be useful to examine, and of particular interest to donors who aim to establish or support groups with a particular orientation. This study focused on those who work within organisations, rather than those served by them. It would be useful to examine, and compare perspectives on frame, and on rights use between the two groups, as well as to conduct further comparisons between national and district or local offices where those exist.

A major finding of this research is the strong and particular personal resonance of rights, which did not appear paralleled by other frames such as development, gender or public health. I, and others before me (see Hopgood 2006) have made a comparison between rights and religion, noting a similar level of belief, commitment, and sometimes evangelical zeal. With this in mind, it would be interesting to examine faith-based groups, using a faith-

motivated frame to examine whether similar factors are at play in how they understand and communicate their work.

There are a host of interesting linguistic questions about local understandings and translations of human rights. Human rights are often posited as a recent and foreign phenomenon, yet they are spoken of in African languages. Where words do not already exist, new meanings arise from what are seen as related terms, as evidenced by the Naro translation of human rights as “how things are being done.”⁵²¹ In examining and locating rights on the African continent, it would be useful to understand how rights are spoken about, and how and whether local understandings are communicated through these conversations. In particular what appears to be the evolving meaning of *botho* / *ubuntu* is of great interest. In some respects it appears to be a localised creation story of rights in the making, whereby rights are increasingly understood as coming from and being grounded in this indigenous concept. Examining the use of these concepts over time and their interaction with rights could provide useful insight into the understudied area of African conceptions of rights.

Finally, this research highlighted the role of the individual leaders but situated these individuals within organisations. Given the prominent role leaders play in the adoption of the rights frame, it would be useful to conduct a longitudinal study examining frame diffusion with the individual as the unit of analysis. Such a study could trace individuals in leadership

⁵²¹ Author's interview, Employee 4, Kuru Family of Organisations, 9 July 2010, D'Kar, Botswana.

positions as they move from organisation to organisation throughout their careers examining their impact on organisational frame.⁵²²

8.4 Conclusion

As stated at the outset, HIV is often, and rightfully, described as a pandemic of devastation. Alongside this high human toll, HIV is also a location of civil society innovation, with regard to the language and form of advocacy as well as the level of international connection. Investigation of this dynamic and evolving site of innovation shows that rights are being understood and employed as tools of agency and citizenship, even in locations of relative isolation. Why groups choose the advocacy frames they do is a question that speaks to our understanding of civil society, our concerns with the impact of health interventions, and our comprehension of the way actors identify themselves and their relationships with other actors including the state. The choice of HIV activists to draw on rights, and the significant break this demonstrates from more traditionally dominant forms of health advocacy is a useful case to examine, both for its own sake, but also with a view to understanding how and why the language of advocacy spreads across different topic areas and different settings. While HIV activists continue to be at the vanguard of this movement, the contagion of rights discourse into health advocacy, and other new fields such as environmental issues, continues. There is now a notable emergence of rights language among health issues which are often addressed alongside HIV, including tuberculosis and reproductive and sexual health. Groups bring their rights with them as they address new issues with BONEA now addressing cervical cancer,

⁵²²This idea was sparked by a presentation given by Charli Carpenter titled "Lost Causes: Agenda-Setting and Agenda-Vetting in Global Issue Networks" on 15 March 2013 at the Liu Institute for Global Issues, University of British Columbia, Vancouver.

ARASA increasing its work on tuberculosis, and TAC addressing more health issues as well as structural factors such as health funding. There is also evidence that groups who began as rights-based HIV organisations, such as South Africa's AIDS Law Project (now Section 27) are now expanding into new topic areas while retaining this rights emphasis. This continued expansion of the topical territory of rights traces the interaction of issues, groups and individuals highlighting personal choices and beliefs in a frame and in the impact it has on the lives of activists and those for whom they campaign.

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Appendices

Appendix A: Methods

A.1 Interview Guide

Note: Interviews will have a semi-structured format, in which I may not ask questions in the same order, may skip questions if they seem irrelevant, or may ask additional questions when interesting topics arise unexpectedly.

Questions for non-governmental organisations

Organisation and Frames

1. In your own words, how would you describe the objectives of your organisation?
2. Your organisation's mission statement/mandate refers/does not refer to human rights. Can you tell me about how the decision made to include/not-include this? Does its inclusion/non-inclusion reflect the actual work of the organisation?
3. When you are involved in education, advocacy and public education activities around HIV do you talk about: Health? Rights? Development? Equity? Charity? Religion? Gender? Are there any key concepts that I have not mentioned that you use?
4. Is any one of these concepts dominant (in your organisation/in this country)?
5. Do you find that you refer to different concepts in different contexts (ie village versus city, with government, with donors, internationally vs nationally, membership events)? If so, why?
6. Have you found that you have drawn on different concepts over time? Why do you think this is the case? Could you give me some examples (with timeline)?
7. Which of these concepts (or others) do you prefer? Why?
8. Does the success/lack of success of other organisations impact on the strategies that your organisation uses? Could you give me an example?
9. Do you know of other organisations that use the same approach as you?
10. How important is training to your organisation? Who do you train? What are the key messages/skills of this training?
11. When your organisation takes on a new issue or begins a new campaign, why does this occur?
12. (For membership organisations) Does your membership impact on the direction of the organisation? (How? through AGM, votes, stakeholders meetings)

International Connections

13. Are you in touch with organisations in other countries with similar mandates? How often?
14. Do you use the internet to find information from groups in other countries doing similar work?
15. Does your organisation participate in international conferences? Which ones? How often? Who from the organisation goes? When was the first conference?

16. Do you have international staff? Volunteers? Consultants? If yes, how long have you had international staff for? If no, have you ever had international staff?
17. Do you feel the way you approach issues been influenced in any way from these international connections? How?

Membership

18. (If a membership-based organisation) How many members does the organisation have? (individual or organisational)
19. Why do you think members/volunteers become involved?
20. Have you recently held an event (rally, protest, campaign)? What was the turnout? Why do you think you received that sort of turn out?

Influencing Decision Makers

21. Would you say that one of your organisation's goals is to influence decision-makers? Could you elaborate (who and on what)?
22. Do you feel that you have been effective in doing so? Why do you feel this was the case? Could you give me an example?
23. What do you think are the critical factors in influencing decision-makers?

Funding

24. Where does this organisation receive its funding from? (time frame, project versus operational funding)
25. Have you found that funders prefer some approaches to HIV over others? Could you give me some examples?

Impact of other domestic non-governmental organisations

26. Are there other groups that do similar work to your organisation in this country/area?
27. Do you find that there is any competition between these organisations and yours? (for what? Funding, press, membership?)
28. What influence if any does this competition have on your organisation?
29. How is your organisation different from other organisations in this field? Do you feel the need to differentiate yourself?
30. Do you see that some organisations are more successful at influencing decision-makers than others? Why do you think this is?
- 31.

Questions for members/participants

1. How long have you been involved with this organisation?
2. Can you describe the nature of your involvement?
3. Why did you become involved? Why in this organisation as opposed to other groups working on the same topic?
4. Can you describe in your own words what this organisation does?
5. Can you describe in your own words what its goals or objectives are?

6. Can you tell me about the current campaigns that this organisation is involved with?
7. How much time in an average week/month do you spend doing work/being involved in activities for this organisation?
8. Do you feel that this organisation is typical or different from other organisations working on HIV in this country?

Questions for United Nations Employees

1. How long have you been in your current position/at the UN?
2. The UN has adopted a rights-based approach in several areas, including the 'rights-based approach to development. Could you describe to me how this approach has impacted on the work that you do?
3. Do you see the rights-based approach as effective? Why or why not?
4. What do you see as the differences (including opportunities and challenges) between a development and human rights approach?
5. What other approaches have you seen at work? Have these been applied to HIV?
6. Do you find that you refer to different concepts in different contexts? If so, why? Have you noticed regional variation?
7. Have you found that you/your agency has drawn on different concepts over time? Why do you think this is the case? Could you give me some examples (with timeline)?
8. Which of these concepts (or others) do you prefer? Why?
9. Does the success/lack of success of other organisations impact on the strategies that the UN uses? Could you give me an example?
10. What changes if any have you noticed in the manner in which HIV is addressed within the UN system?
11. What changes do you see this as having on grass-roots organisations?

For domestic government officials/decision-makers

1. Can you describe your position/job? How long have you been in this position?
2. Can you describe your role with respect to policy creation/amendment?
 - with respect to amending and creating laws?
 - with respect to implementing policies and programmes?
3. When it comes to changing the ways laws and policies are written and/or enforced where would you say the push for change most often comes from?
4. Does change frequently come about due to public mobilisation? NGO activity? Press coverage?
5. Can you give me an example of public mobilisation leading to policy change/change in implementation? Why do you think this occurred?
6. Can you give me an example of mobilisation that you are aware of that did not result in policy change? Why do you think this occurred?
7. Does the way in which an issue is presented impact on whether or not it leads to policy change?

8. Of the following which ways of speaking about issues relating to HIV do you feel are the most effective: Charity? Health? Development? Human rights? Religion? Gender? (any others?)
9. What do you think about the human rights approach to HIV/AIDS? Do you feel it is effective? Appropriate?
10. Does where the push for change originates impact on whether or not policies/laws/implementation changes? (inside or outside of the country)
11. How would you describe your relationship with the NGO sector? With relation to HIV?
12. Who would you identify as the critical actors with relation to HIV in this country? With relation to health?
13. Could you briefly describe your government's strategy for dealing with the HIV pandemic?

Communicating Findings (for all interviewees)

1. Would you like to be notified about the results of this study?
2. What would be a useful way for you to be notified (ie for example, a talk, a workshop, poster, report or briefing documents, reading the thesis)?
3. What language would you prefer?
4. As you know this study is looking at how civil society groups in sub-Saharan Africa mobilise and advocate on issues related to HIV/AIDS – specifically, what information on this topic would be useful to you in the work that you do?

A.2 Coding

Document Families

Country:

BOTSWANA: Botswana

UGANDA: Uganda

SAFRICA: South Africa

REG: Regional (ie SAfAIDS, ARASA, SADC PF)

GHANA: Ghana

OTH: ie UN, Paul Hunt

NGO: a non-governmental organisations

GOVT: a government representative

IO: International Organisation (ie UN or International NGO)

DONOR: Funding Organisations

Frames:

ORG-RIGHTS : Organisation's Main Frame is Rights

ORG-COMBO: Organisation's Main Frame is a Combination of Rights and Something Else

ORG-OTHER: Organisation's Main Frame is Something Other than Rights

INDIV-RIGHTS: Individual respondent's main frame is rights

INDIV-COMBO: Individual respondent's main frame is rights in combination with something else

INDIV-OTHER: Individual respondent's main frame is something other than rights

Codes

HYPOTHESIS-BASED

FRAMES:

FGENDER: mention of gender frame

FDEVELOP: mention of development frame

FPHEALTH: mention of public health frame

FOTHERFR: Other Frame (Equity, religion, etc.)

FHRDOMFRAME: Domestic human rights frame

REASONS:

RRALLYCALL: human rights language used because members response to it, it is a mobilisation tool

RMOB: discussion about mobilisation

RTRUEBELIEVER: True Believer, individuals discuss use of human rights language because they believe in it

RNICHE: Organisations favour a HR approach because it sets them apart from other organisations

RLOWERINFECT: use of human rights language because it was thought to lower the infection rate

REMPOW: use of human rights language because it was thought to empower membership or participants

DONORS:

DHR+DONOR: Donors like a rights-based approach

DHR-DONOR: Donors dislike a rights-based approach

DADV+DONOR: Donors like funding advocacy

DADV-DONOR: Donors dislike funding advocacy

HUMAN RIGHTS:

HRADV: Advantages to a HR approach

HRDIS: Disadvantages to a HR approach

HBOTH: human rights as having a basis in local concepts such as botho or ubuntu

INTERNATIONAL:

INTLCONNECT: International Connection

INOINTL: No international connection (or limited)

INEW IDEAS: New ideas through international connection

OTHER

MEMBER: Discussion of membership

INFL+ GOV: positive influence/interaction with government

INF-LGOV: negative influence/interaction with local government

ONEWIDEAS: New ideas from sources other than international connections

GOODQUOTE: A good quotation that I may want to use in my writing

KEYMSG: Key message of a campaign or for an organisation

OBJHR: human rights in organisational objectives

OBJOTH: Human rights not listed as being in organisational mandate or purpose

INDUCTIVE:

PROCESS: human rights as process

HRMARG: human rights as linked with marginalisation

LGBT: lesbian, gay, bisexual, transgendered, intersex

SEX WORK: sex workers

PRISON: discussion of prison or prisoners

TB: tuberculosis

SRH: Sexual and reproductive health

ABOUT: people talking about other organisations

CHANGE- either over time or by audience

A.3 Detailed Breakdown of Classification Grid

Cases are examined with reference to five categories: (1) rights in purpose, (2) rights in print and rights on display, (3) rights in action, (4) rights in context and time, and, (5) rights in speech. Each of these categories and methods of measurement is outlined below, and each holds particular strengths and weaknesses. The aim of using five different measures (some of which include sub-measures) to classify the nine organisations examined is to present a well-rounded portrayal of rights use in each group, and to choose measures whose strengths and weaknesses are likely to offset and complement each other.

One of the difficulties in comparing data systematically across nine diverse organisations is the variation in both data quantity and form. All efforts have been made to compare like data, however, this effort had to be balanced with the availability of data across cases. This was done so as to minimise the number of instances where one or more cases had to be excluded due to lack of data. Where data is not available in any one sub-measure, that sub-measure is excluded from the tally. The score from the available data is converted into a percentage, and then into a score out of twenty.

Rights in Purpose

Rights in purpose is based on the inclusion of rights in the organisation's mandate or objectives in both formal (/10) and informal settings (/10). Half of this categorization is based on the inclusion of rights in the group's listed mandate, objectives, vision, values or equivalent statement. If rights are absent, the group scores a zero, if rights are present but not dominant it scores a 5 and if rights are dominant the organisation scores a 10. Because organisational statements may be somewhat static reflections of organisational identity, the second half of the score is based on the perspective of interview respondents. Each respondent who noted rights as the sole dominant frame scored a 1, where rights was referenced as dominant in conjunction with one or more other frames each respondent scored 0.5. The scores were tallied, divided by the number of respondents (or, where not all respondents answered this question, by all respondents who did). This number was converted to a percentage, and rounded to the nearest full number. The two scores out of ten are added for a score out of twenty.

Table 14: Rights in Purpose

Organisation	Rights in Mandate (0 not there, 5 mentioned not prominent, 10 prominent)	% of respondents who list rights as a dominant approach (1 if alone, .5 if with another approach) Rounded	Score /20
BONELA	10	$6.5/10 = 65\% = 7/10$	17
ARASA	10	$2/4 = (50\%) = 5/10$	15
TAC	10	$6/10 = 60\% = 6/10$	16
NACWOLA	5	$1/4 = (25\%) = 3/10$	8
SAfAIDS	5	$.5/3 (17\%) = 2/10$	7
TASO	5	$2.5/7 (36\%) = 4/10$	9
NAP+	5	$1/5 (20\%) = 2/10$	7
WUAAG	0	$.5/3 (17\%) = 2/10$	2
Kuru	0	$0 = 0\% = 0/10$	0

Rights in Print and Rights on Display

Rights in print examines the reference to rights in organisational materials, with an emphasis, where possible, on dynamic materials that reflect contemporary rather than historical organisational perspectives. The first half of this category examines frequency of rights in newsletters, or, where newsletters were not produced, annual reports, pamphlets or equivalent documents.⁵²⁴ Rights in print is a simple and non-analytical measure, searching for the frequency of the word ‘rights’ in organisational documents. This method does analyse context and may slightly under-represent rights as ‘right’ and ‘right to’ may also refer to human rights. In contrast with these two terms, however, ‘rights’ is unlikely to over-represent rights use as it has very few other meanings.

The second sub-measure examines displayed rights including posters and other materials displayed on the walls of organisational offices. This measure is likely to capture more locally and externally-oriented materials (as annual reports may be directed at the board of directors and/or donors). Displayed materials are an act of self-representation indicating how the group sees itself, and wishes others to see it when they visit their premises. Here materials are analysed for content rather than simply conducting a word count. Both materials created by the organisation, and those created externally but displayed internally are included in this measure. In all instances isolating internally produced from externally produced materials would not alter scoring.

⁵²⁴ There is a significant variation in the availability of print materials across these groups. Newsletters were the first choice document of analysis and were analysed (based on availability) from inception to the end of 2011 (BONELA, TAC, ARASA, SAfAIDS), where these did not exist annual reports were utilised (Kuru). Where no formal annual reports were available, documents that were similar to annual reports were used (NACWOLA, TASO, NAP+). Where no such documents existed pamphlets were analysed (WUAAG).

Table 15: Rights in Print and Rights on Display

Organisation	Organisational documents	Displayed Rights	Score /20
	More than once a page = 10/20 Once every 2-5 pages = 5 Less than once every 5 pages	Most displayed materials feature rights: 10 Some displayed materials feature rights: 5 No displayed materials feature rights:0	
BONELA	4 times per page = 10/10	10	20
ARASA	3 times per page = 10/10	5	15
TAC	Once every three pages = 5/10	5	10
NACWOLA	Once every 1.5 pages = 5/10	5	10
SAfAIDS	0.48, just under once every two pages =5/10	5	10
TASO	0.27 (just over once every 4 pages) = 5/10	5	10
NAP+	0.03 (roughly once every 30 pages) = 0/10	0	0
WUAAG	0 = 0/10	5	5
Kuru	Once every 10.26 pages= 0/10	0	0

Rights in Action

Rights in action looks specifically at campaign messages, examining whether rights are the dominant frame in campaigns over the group's history (/10), whether at least one current campaign refers to rights (/10). In contrast with organisational objectives or printed materials, rights in action is an attempt to gauge active use of rights as a tool of activism. While in some cases there is overlap between these categories, or the creation of printed materials in relation to campaigns, in others the written and oral reflections of organisations are quite different. Rights in action is an attempt to gauge active use of rights as a tool of activism.

Table 16: Rights in Action

Organisation	Rights a dominant frame in campaigns (/10)	1+ Current campaign/project (/10)	Score (/20)
BONELA	10	10	20
ARASA	10	10	20
TAC	10	10	20
NACWOLA	0	10	10
SAfAIDS	0	10	10
TASO	0	Insufficient Data	0
NAP+	0	Insufficient Data	0
WUAAG	0	0	0
Kuru	0	0	0

Rights in Context and Time

Rights in Context and Time examines the use of rights in different contexts and time periods. Half of the score is based on use of rights in different settings including interventions with communities and government, locally-oriented advocacy, nationally-oriented interventions, and international activities and communication with donors. The second half of the score out

of 20 is based on temporal consistency with 10 points given for consistent reference to rights over the timeline of the organisation, based on documentary evidence and interviews.

Table 17: Rights in Context and Time

Organisation	Consistency Across Settings (/10) Rights are Used in all or Virtually all Settings (10) Rights are Used in Some Settings (5) or, Rights are used on some topics across Settings Rights are not used (0)	Consistency Over Time Rights are used throughout organisational history as a dominant frame (10) Rights are used substantially more in one time period than others (5) Rights are used amid other frames consistently over time (5) Rights are not used (0)	Score
BONELA	10	10	20
ARASA	10	10	20
TAC	10	10	20
NACWOLA	5	5	10
SAfAIDS	5	5	10
TASO	5	5	10
NAP+	5	Insufficient data	5/10 = 10/20
WUAAG	0	0	0
Kuru	0	0	0

Rights in Speech

Rights in speech focuses on interview data.⁵²⁵ Half of the score focuses on the frequency of rights references, examining how often respondents mentioned rights in interviews. The second half of the score measures unsolicited references, in an attempt to provide some control for respondents who made reference to rights only when asked or, for example, had a tendency to repeat the questions they were asked. Rights in speech would be expected to over-represent rights usage as respondents were aware of the focus and purpose of the research (as it was stated in the letter of initial contact and the consent forms). However, the significant variation in the frequency of rights references indicates that this measure likely does yield meaningful information.

⁵²⁵ In line with the analysis of print documents, interviews/interview transcripts were scanned for the word 'rights' used by the interviewee. Where interviews were conducted with more than one person at the same time, for the purposes of this classification the interview is counted as one interview, with the total number of references by respondents divided by the number of minutes. As such, the number of interviewees may not correspond with the number of interviewees listed elsewhere in the thesis, where each person is counted separately and responses are coded accordingly. Where interviews were not recorded, no word count was carried out, though notes were consulted to ascertain whether the interview is consistent or inconsistent with recorded interviews for that organisation.

Table 18: Rights in Speech

Organisation	Frequency of rights mentions (number of references divided by number of minutes ⁵²⁶) by interviewee	Average frequency /10	Solicited/unsolicited /10	Score
		More than every 3 minutes: 10 Every 3 -6 minutes: 8 Every 6- 9 minutes: 6 Every 9 – 12 minutes: 4 Every 12-15 minutes: 2 Less than once every 15 minutes: 0	Substantial unsolicited by most respondents: 10 Substantial unsolicited by some respondents: 8 Some unsolicited by most respondents: 6 Some unsolicited by some respondents: 4 Minimal unsolicited: 2 No unsolicited: 0	
BONELA	A: 1.68 B: 0.76 C: 1.95 D: 2.19 E: 0.68 F: 1.61 G: 0.86 H: 2.91 I: 0.89 J: 1.33 K: 4.46 L: unrecorded, unsolicited references	Every 1.76 minutes = 10/10	10	20
ARASA	A: 0.60 B: 1.51 C: 1.25	Every 1.21 minutes = 10/10	8	18
TAC	A: 1.7 B: 5.3 C: 2.45 D: 3.07 E: 3.47 F: 3.3 G: 10.6 F: unrecorded, unsolicited references	Every 4.27 minutes = 8 /10	8	16
NACWOLA	A: 0.52 B: 0.52 C: 0.84 D: 2.77 E: unrecorded, unsolicited references	Every 1.63 minutes = 10/10	6	16
SAfAIDS	A: 2.29 B: 1.07	Every 1.68 = 10/10	6	16

⁵²⁶ The lower the number the more frequent the rights references, ie 0.52 indicates rights are referred to approximately twice a minute, whereas 21.33 indicates rights were mentioned only about once every 21 minutes. Where no rights references were made this is indicated and the number entered is the length of the interview.

Table 18: Rights in Speech

Organisation	Frequency of rights mentions (number of references divided by number of minutes ⁵²⁷) by interviewee	Average frequency /10	Solicited/unsolicited /10	Score
		More than every 3 minutes: 10 Every 3 -6 minutes: 8 Every 6- 9 minutes: 6 Every 9 – 12 minutes: 4 Every 12-15 minutes: 2 Less than once every 15 minutes: 0	Substantial unsolicited by most respondents: 10 Substantial unsolicited by some respondents: 8 Some unsolicited by most respondents: 6 Some unsolicited by some respondents: 4 Minimal unsolicited: 2 No unsolicited: 0	
TASO	A: 1.06 B: 9.25 C: 21.33 D: 3.14 E: 1.04 F: 7 G: 9.75 H: 1.69 I: 2.3 J: 10.5	Every 6.71 = 6/10	6	12
NAP+ ⁵²⁸	A: 4.14 B: 9 C: 3.38 D: 15 E: 6	Every 7.05 = 6/10	2	8
WUAAG	A: 5.5 B: 1.91 C: 9.3	Every 5.57 = 8/10	2	10
Kuru	A: 11.9 B: 51 (no references) C: 9.75 D: 7.29 E: unrecorded, no unsolicited F: unrecorded, no unsolicited G: unrecorded, no unsolicited	Every 19.99 = 0 /10	0	0

⁵²⁷ The lower the number the more frequent the rights references, ie 0.52 indicates rights are referred to approximately twice a minute, whereas 21.33 indicates rights were mentioned only about once every 21 minutes. Where no rights references were made this is indicated and the number entered is the length of the interview.

⁵²⁸ There was a tendency of groups in Ghana to repeat questions asked, sometimes resulting in relatively high word counts despite quite low rights emphasis.

Overall Classification

Scores from the measures earlier above are tabulated in the chart below. The organisations were sorted into three categories (rights dominant, rights mixed and rights limited) based on natural break points in the scores among the nine groups. These scores indicate rough evaluations useful for the purpose of classifying these organisations into groups with regards to the use of the rights frame. They cannot be understood as definitive numbers that can be used in mathematical or statistical comparison, ie a group with a score of 80 is not, for example, twice as likely to refer to rights as one with a score of 40. The significant breaks between the categories do, however, indicate meaningful variation in the use of the rights frame.

While efforts were made to accurately represent organisations, including interviews with a broad cross-section of employees, and in different locations,⁵²⁹ with respect to groups with multiple offices (in particular, TAC, NACWOLA, TASO and NAP+) it is possible that the findings which are location-based (ie interview and observation-based data) may vary by office.⁵³⁰

Table 19: Overall Classification

Organisation	Rights in purpose	Rights in print and rights on display	Rights in action	Rights in context and time	Rights in speech	Total
BONELA	17	20	20	20	20	97
ARASA	15	15	20	20	18	88
TAC	16	10	20	20	16	82
NACWOLA	8	10	10	10	16	54
SAfAIDS	7	10	10	10	16	53
TASO	9	10	0	10	12	41
NAP+	7	0	0	10	8	25
WUAAG	2	5	0	0	10	17
Kuru	0	0	0	0	0	0

⁵²⁹ Interviews were carried out in two TAC offices (one district office and the head office), in two NAP+ locations (head office, and one district location (no office)), in one TASO location encompassing both the head office and a local office (TASO Mulago) as well as with one visiting employee from another office (Entebbe), and in one NACWOLA office (head office).

⁵³⁰ Interviews were carried out in two TAC offices (one district office and the head office), in two NAP+ locations (head office, and one district location (no office)), in one TASO location encompassing both the head office and a local office (TASO Mulago) as well as with one visiting employee from another office (Entebbe), and in one NACWOLA office (head office).

A.4 Communication of Research Findings

Academic and Other Communities Outside of the Regions Studied	<ul style="list-style-type: none"> • <i>Health Advocacy on the Margins</i>, Canadian Political Science Association Conference, Victoria, B.C., 6 June 2013. • <i>Choosing Rights: The Puzzle of the Rights Frame in HIV Advocacy</i>, International Studies Association Annual Convention, San Francisco, California, U.S., 4 April 2013. • <i>HIV Advocacy in sub-Saharan Africa: Experiences of Empowerment and Desperation</i>, Canadian Association of HIV Research Annual Conference (ancillary event), Montreal, Quebec, 22 April 2012. • <i>Choosing Rights: The Puzzle of the Rights Frame in HIV Activism: Preliminary Reflections from Ghana & Uganda</i>. Human Rights Centre, University of Essex, Colchester, U.K. 11 June 2010. • <i>Media & Policy: A Comparison & Examination of Media Messages & HIV Policy in Botswana, Ghana & Uganda</i>, Poster Presentation, XVIII World AIDS Conference, Vienna, Austria, 20 July 2010. • <i>When Who You are Makes Times Hard: Marginalisation, Human Rights & NGO Mobilisation on Health Issues</i>, American Political Science Association Conference, Washington, D.C. 4 September 2010. • <i>The Potential & Pitfalls of the Millenium Development Goal Framework</i>, World University Service of Canada Annual Assembly, Ottawa, Ontario, 7 November 2010. • <i>Advocacy in Context: Human Rights and HIV in Settings of Confrontation and Consensus</i>, Canadian Political Science Association Conference, Wilfrid Laurier University, Waterloo, Ontario, 18 May 2011.
Academic and Other Communities Inside the Regions Studied	<ul style="list-style-type: none"> • <i>Reasons for Rights: A Qualitative Approach to Rights Use Among HIV Advocacy Groups</i>, 20th Anniversary of the Human Rights Centre Conference, Human Rights Centre, University of Pretoria, Pretoria, South Africa, 3 June 2011.
Research Participants and Participating Organisations (with a particular emphasis on case study organisations)	<ul style="list-style-type: none"> • <i>Presentation of Preliminary Findings</i>, Botswana Network on Ethics, Law and HIV/AIDS, Gaborone, Botswana, 26 June 2011. • Mailed two audio CDs of interviews to interviewees who requested this in order to share with their support groups. • Two comprehensive emails including list serves, resources, organisations and institutions active in this field, to those who requested it (primarily respondents in Ghana and Uganda). • Periodic email research updates to research participants

Appendix B: Primary Sources

B.1 Interview List

Interviews⁵³¹

1) Botswana⁵³²

Botswana Network on Ethics, Law and HIV/AIDS (BONELA)

Author's interview, Uyapo Ndadi, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 27 June 2010, Gaborone, Botswana.

Author's interview, Program Manager, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 28 June 2010, Gaborone, Botswana.

Author's interview, Anna Mmolai-Chalmers, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 29 June 2010, Gaborone, Botswana.

Author's interview, Doris N. Kumbawa, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 30 June 2010, Gaborone, Botswana.

Author's interview, Dikeledi Dingake, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 6 July 2010, Gaborone, Botswana.

Author's interview, Christine Stegling, Former Director, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 24 January 2011, Brighton, United Kingdom.

Author's interview, Employee 1, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 22 June 2010, Gaborone, Botswana.

Author's interview, Employee 2, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 23 June 2010, Gaborone, Botswana.

Author's interview, Employee 3, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 28 June 2010, Gaborone, Botswana.

⁵³¹ All interviews were conducted by the author. In all settings, save South Africa, interviewees were given the option of identifying themselves by name and organisation, by organisation only, or without identifying the organisation. Respondents who had other preferences (for example by name but not by organisation, by first name only, by position rather than name) were cited as such. In South Africa, in accordance with national ethics regulations respondents were only given the choice of being identified by organisation or not, however, where respondents specifically requested being identified by their personal name they were permitted to do so.

⁵³² One interview under the Botswana category was conducted in Vienna, Austria but is listed here as having taken place in Gaborone as listing the location would identify the respondent. One additional interview took place with a BONELA employee who wished to be cited in an alternative fashion not identifying the organisation.

Author's interview, Employee 4, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 29 June 2010, Gaborone, Botswana.

Author's interview, Employee 5, Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 28 June 2010, Gaborone, Botswana.

Kuru Family of Organisations

Author's interview, Laura Martindale, Kuru Family of Organisations, 5 July 2010, D'Kar, Botswana.

Author's interview, Elizabeth Gaehore, Kuru Family of Organisations, 8 July 2010, D'Kar, Botswana.

Author's interview, Willie Freddy Morris, Kuru Family of Organisations, 8 July 2010, D'Kar, Botswana.

Author's interview, Keletlhokile Sedumabo, Kuru Family of Organisations, 8 July 2010, D'Kar, Botswana.

Author's interview, Susan Mothibi, Kuru Family of Organisations, 8 July 2010, D'Kar, Botswana.

Author's interview, Employee 1, Kuru Family of Organisations, 6 June 2011, D'Kar, Botswana.

Author's interview, Employee 2, Komku Trust, Kuru Family of Organisations, 8 July 2010, D'Kar, Botswana.

Author's interview, Employee 3, Kuru Family of Organisations, 8 July 2010, D'Kar, Botswana.

Author's interview, Employee 4, Kuru Family of Organisations, 9 July 2010, D'Kar, Botswana.

Other Organisations

Author's interview, Prisca Skipper Mogapi, LGBTI activist in Botswana, 29 June 2010, Gaborone, Botswana

Author's interview, Diana Meswele, Human Rights Activist, 13 July 2010, Gaborone, Botswana.

Botswana Council of NGOs (BOCONGO)

Author's interview, Employee 1, Botswana Council of NGOs (BOCONGO), 12 July 2010, Gaborone, Botswana.

Botswana National Association of AIDS Service Organisations (BONASO)

Author's interview, Employee, Botswana National Association of AIDS Service Organisations (BONASO), 23 July 2010, Botswana.

Botswana Network of People Living with HIV/AIDS (BONEPWA)

Author's interview, Zolani A. Kraai, Botswana Network of People Living with HIV/AIDS (BONEPWA), 6 July 2010, Gaborone, Botswana.

District Multi Sectoral AIDS Committee (DMSAC), Ghanzi District

Author's interview, Lesedi, Program Officer, Ghanzi District, District Multi Sectoral AIDS Committee (DMSAC), 9 July 2010, Ghanzi, Botswana.

Author's interview, Senior Monitoring and Evaluation Officer, District Multi Sectoral AIDS Committee (DMSAC), 9 July 2010, Ghanzi, Botswana.

Ditshwanelo – The Botswana Centre for Human Rights

Author's interview, Alice Mogwe, Director, Ditshwanelo – The Botswana Centre for Human Rights, 30 June 2010, Gaborone, Botswana.

Author's interview, Fundraising and Communications Coordinator, Ditshwanelo – The Botswana Centre for Human Rights, 30 June 2010, Gaborone, Botswana.

Forum Syd

Author's interview, Martin Mosima, Forum Syd, 5 July 2010, Gaborone, Botswana.

Ministry of Health

Author's interview, T. Motsemme, Ministry of Health, 15 July 2010, Gaborone, Botswana

Author's interview, Employee 1, Ministry of Health, 9 July 2010, D'Kar, Botswana.

National AIDS Coordinating Agency (NACA)

Author's interview, Employee 1, National AIDS Coordinating Agency (NACA), 14 July 2010, Gaborone, Botswana.

Author's interview, Employee 2, National AIDS Coordinating Agency (NACA), 15 July 2010, Gaborone, Botswana.

National AIDS Council

Author's interview, Festus G. Mogae, National AIDS Council, 13 July 2010, Gaborone, Botswana.

Stepping Stones International

Author's interview, Lila Pavey, Stepping Stones International, 13 July 2010, Botswana.

Tertiary Education Council

Melissa Godwaldt, Tertiary Education Council, 30 June 2010, Gaborone, Botswana.

True Love Waits (Ghanzi)

Author's interview, Employee 1, True Love Waits, 9 July 2010, D'Kar, Botswana.

Author's interview, Employee 2, True Love Waits, 9 July 2010, D'Kar, Botswana.

World University Service of Canada (WUSC)

Author's interview, One Morapedi, World University Service of Canada (WUSC), 24 June 2010, Gaborone, Botswana.

2) South Africa**Treatment Action Campaign (TAC)**

Author's interview, Rebecca Hodes, Former Employee, Treatment Action Campaign (TAC) Head Office, 21 June 2011 (Telephone interview), Cape Town, Western Cape, South Africa.

Author's interview, Nontyatyambo Makepela, Treatment Action Campaign (TAC) Ekurhuleni District Office, 10 August 2010, Ekurhuleni, Gauteng, South Africa.

Author's interview, Employee 1, Treatment Action Campaign (TAC) Ekurhuleni District Office, 3 August 2010, , Ekurhuleni, Gauteng, South Africa.

Author's interview, Employee 2, Treatment Action Campaign (TAC) Head Office, 17 June 2011, Cape Town, Western Cape, South Africa.

Author's interview, Employee 3, Treatment Action Campaign (TAC) Head Office, 17 June 2011, Cape Town, Western Cape, South Africa.

Author's interview, Employee 4, Treatment Action Campaign (TAC) Ekurhuleni District Office, 10 August 2010, Ekurhuleni, Gauteng, South Africa.

Author's interview, Employee 5, Treatment Action Campaign (TAC) Ekurhuleni District Office, 25 August 2010, Ekurhuleni, Gauteng, South Africa.

Author's interview, Employee 6, Treatment Action Campaign (TAC) Ekurhuleni District Office, 25 August 2010, Ekurhuleni, Gauteng, South Africa.

Author's interview, Employee 7, Treatment Action Campaign (TAC) Ekurhuleni District Office, 25 August 2010, Ekurhuleni, Gauteng, South Africa.

Other Organisations**AIDS Law Project**

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B.3 Materials Observed (Wall Materials and Billboards)

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Posters

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e) D’Kar Museum

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f) Kuru Family of Organisations

Posters

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Ministry of Health. *Ke Emisa TB! Le wena o ka kgona*. In Setswana. *I’m Stopping TB! You Can!* [Translated Title]. Observed at Kuru Family of Organisations, D’Kar: Botswana, July 2010.

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Kuru Family of Organisations. *Ke Emisa TB – Stop TB*. In Setswana and English. T-shirt. Observed at Kuru Family of Organisations, D’Kar: Botswana, July 2010.

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Kuru Family of Organisations. *Kaputura Map*. Observed at Kuru Family of Organisations, D’Kar: Botswana, July 2010.

Kuru Family of Organisations. *Directions to Dobe and Surrounding Settlements*. Observed at Kuru Family of Organisations, Botswana, July 2010.

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Education Starts at Home. Talk to Your Kids. Teach Them Morals, Respect and Responsibility. Enforce the Importance of Getting an Education and to Care About School. Invest in Your Children. Signage. Observed at Kuru Family of Organisations, D’Kar: Botswana, July 2010.

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Shelf of 19 Different Type of Pamphlets Containing Information on HIV, Rape, TB and Bokamoso Trust. Shelf containing pamphlets. Observed at Kuru Family of Organisations, D’Kar: Botswana, July 2010.

Elderly Woman Holding a Wooden Walking Stick. Painting. Observed at Kuru Family of Organisations, D’Kar: Botswana, July 2010.

Activist Speaking on Stage with Banners at the Background. Banners State “Stop TB” and “Accommodating your Future”. Photograph. Observed at Kuru Family of Organisations, D’Kar: Botswana, July 2010.

Teen Club. *Teen Talk – Bukona ya go Tshela Botshelo jo ba Lalameng*. In English and Setswana. *Teen Talk- A Booklet About Living a Positive Lifestyle*. [Translated title]. Magazine. Observed at Kuru Family of Organisations, D’Kar: Botswana, July 2010.

ToCaDi. *ToCaDi – World AIDS Day Commemoration 2008*. Newsletter. Observed at Kuru Family of Organisations, D’Kar: Botswana, July 2010.

2) South Africa

a) Treatment Action Campaign

Posters

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Treatment Action Campaign (TAC). *I-Fluconazole yelapha amalovula emionyeni, emminzweni kanye nasesithweni sangasese sowesifazane kanye ne-cryptococcal meningitis (isifo solwembu lobuchopho nomgogodia)*. In Zulu. *Fluconazole Treats Thrush in Mouth, Foodpipe, and Vagina and Cryptococcal Meningitis* [Translated title]. Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Germiston, Gauteng: South Africa, August 2010.

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Treatment Action Campaign (TAC). *Know Your Medicines By Name*. Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Germiston, Gauteng: South Africa, August 2010.

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Treatment Action Campaign (TAC). *Vision, Mission and Strategic Approach*. Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Germiston, Gauteng: South Africa, August 2010.

Treatment Action Campaign (TAC). *AIDS Profiteer – John Kearney, CEO, Glaxo SmithKline SA – Deadlier Than The Virus*. Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Germiston Office, Gauteng: South Africa.

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Treatment Action Campaign (TAC). *For a Person Living with HIV – Contrimoxazole Can Be Life Saving*. Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Germiston, Gauteng: South Africa, August 2010.

Treatment Action Campaign (TAC). *Opportunistic Infections Can Be Treated*. Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Germiston Office, Gauteng: South Africa.

Treatment Action Campaign (TAC). *President Mbeki, AZT/Nevirapine for Pregnant Women with HIV*. Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Germiston Office, Gauteng: South Africa, August 2010.

Treatment Action Campaign (TAC). *Constitutional Court – Johannesburg*. Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Germiston, Gauteng: South Africa, August 2010.

Treatment Action Campaign (TAC). *Minister Manto Tshabalala-Msimang – HIV/AIDS Treatment Now. AZT/Nevirapine For Pregnant Mothers with HIV/AIDS* [No formal title]. Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Germiston, Gauteng: South Africa, August 2010.

Treatment Action Campaign (TAC). *Talk About Nutrition & HIV*. Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Germiston, Gauteng: South Africa, August 2010.

Treatment Action Campaign (TAC). *Know Your Medicines By Name*. Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Germiston, Gauteng: South Africa, August 2010.

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Treatment Action Campaign (TAC). *Implement a National HIV/AIDS Treatment and Prevention Plan – Stop New Infections Treat HIV in 2003*. 2003. Observed at Ekurhuleni District Office, Germiston, Gauteng: South Africa, August 2010.

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AIDS Law Project. *HIV/AIDS Know Your Rights!* Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Germiston, Gauteng: South Africa, August 2010.

Treatment Action Campaign (TAC). *HIV/AIDS Treatment Plan Now!* Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Germiston, Gauteng: South Africa, August 2010.

Treatment Action Campaign (TAC). *Why Civil Disobedience is Necessary*. Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Germiston, Gauteng: South Africa, August 2010.

Treatment Action Campaign (TAC). *Fund AIDS – Not War*. Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Germiston, Gauteng: South Africa, August 2010.

A Country for My Daughter. Film Poster. Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Germiston, Gauteng: South Africa, August 2010.

Steps You Should Take to Protect Your Health. Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Germiston, Gauteng: South Africa.

US President Barack Obama and First Lady Michelle Obama Know Their Status...Know Your HIV Status!... Do You and Your Partner Know Yours? Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Germiston Office, Gauteng: South Africa, August 2010.

Department of Health. *Anti-Retroviral Medication [ARV] for Survivors of Sexual Abuse. Health for a Better Life!* Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Germiston, Gauteng: South Africa, August 2010.

PSI Campaign for Migrant Workers' Rights. *December 18 is International Migrants Day! Join the Campaign for Ethical Recruitment of Health Workers*. Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Germiston, Gauteng: South Africa, August 2010.

AntiRetroviral Drug Chart. Poster. Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Germiston, Gauteng: South Africa, August 2010.

One World, One Hope, One Condom. Poster. Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Germiston, Gauteng: South Africa, August 2010.

Photocopies of Political Cartoons

Good Luck 2007. Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Germiston, Gauteng: South Africa, August 2010.

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Zapiro (artist). *Ignoramus - Manto Tshabalala-Msimang, Congress of South African Trade Unions*. Political Cartoon. Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Germiston, Gauteng: South Africa, August 2010.

Zapiro (artist). *Negative Result*. Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Germiston, Gauteng: South Africa, August 2010.

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Department of Health. Zeeman, H. *Letter Addressed to Whom It May Concern on Three Months' Supply of ARV Medicines.* 2 July 2010. Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Germiston, Gauteng: South Africa, August 2010.

Photographs

Treatment Action Campaign (TAC). *Nelson Mandela Wearing a T-Shirt Entitled 'HIV Positive – Issued by Treatment Action Campaign'.* Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Germiston, Gauteng: South Africa, August 2010.

Series of 16 photographs relating to Treatment Action Campaign (TAC) Activities and Demonstrations. Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Germiston, Gauteng: South Africa, August 2010.

Treatment Action Campaign (TAC). Group of Protesters Wearing T-Shirts Entitled 'HIV Positive' and Carrying Banners Entitled 'Wanted – Manto Tshabalala-Msimang and Alec Erwin For Not Stopping 600 HIV/AIDS Deaths Every Day.' Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Germiston, Gauteng: South Africa, August 2010.

Other Wall Materials

Treatment Action Campaign (TAC). *Discussions, Ideas and Questions* [no formal title]. Discussion Notes. Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Germiston, Gauteng: South Africa, August 2010.

Treatment Action Campaign (TAC). *Get Tested for TB. It Can Be Cured.* In Zulu. Leaflet. Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Germiston, Gauteng: South Africa, August 2010.

Treatment Action Campaign (TAC). *Sonke singakwazi ukuzivjela ku-TB.* In Zulu. *Get Tested for TB. It Can Be Cured* [Translated title]. Leaflet. Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Germiston, Gauteng: South Africa, August 2010.

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Kaiser Family. *The Nelson Mandela Award for Health and Human Rights to the Treatment Action Campaign*, October 2003, Framed Award. Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Germiston, Gauteng: South Africa, August 2010.

Does HIV Look Like Me? Series of 9 leaflets depicting different images of men and women. Leaflets. Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Germiston, Gauteng: South Africa, August 2010.

Treatment Action Campaign (TAC). *Vision and Mission of TAC*. Signage. Observed at Treatment Action Campaign (TAC) Ekurhuleni District Office, Germiston, Gauteng: South Africa, August 2010.

b) Billboards

Brothers For Life. *In the Name of Life Always Play it Safe*. Observed at Johannesburg, Gauteng: South Africa, August 2010.

Brothers For Life. *Be a Man Who Takes No Chances and Always Uses a Condom*. Observed at Pretoria, Gauteng: South Africa, August 2010.

c) Department of Health

Posters

Multisectoral Aids Unit. *We Can Stop HIV – We Can All Take Responsibility for Our Sexual Behaviour – All of Us Can Take Action to Reduce New HIV Infections!* Observed at Department of Health, Johannesburg, Gauteng: South Africa, August 2010.

Talk and Act. TALK Honestly About HIV and AIDS. ACT to Protect Yourself and Your Loved Ones from HIV. Observed at Department of Health, Johannesburg, Gauteng: South Africa, August 2010.

Department of Health. *We Are Reducing New HIV Infections in Youth and Babies..* Observed at Department of Health, Johannesburg, Gauteng: South Africa, August 2010.

Department of Health. *Children Are Affected by AIDS in the Family and Need our Help*. Poster. Observed at Department of Health, Johannesburg, Gauteng: South Africa, August 2010.

Department of Health. *Fact Sheet on Influenza*. Observed at Department of Health, Johannesburg, Gauteng: South Africa, August 2010.

3) Uganda

a) Uganda AIDS Commission

Posters

Young Empowered and Healthy. *Take the Lead on HIV and AIDS – “Educators’ Response” – Know Your Sero Status.* Observed at Uganda AIDS Commission, Kampala: Uganda, March 2010.

Young Empowered and Healthy. *“Something for Something” Love. Uncle Bob Gave Me Nice Clothes and Now I am Losing My Future Husband. Short Term Gain, Long Term Loss.* Observed at Uganda AIDS Commission, Kampala: Uganda, March 2010.

Young Empowered and Healthy. *“Something for Something” Love. Uncle Bob Gave Me a Mobile Phone and This Pregnancy. Short Term Gain, Long Term Loss.* Observed at Uganda AIDS Commission, Kampala: Uganda, March 2010.

Young Empowered and Healthy. *“Something for Something” Love. Uncle Got a Few Moments of Pleasure and ... Trouble. Short Term Gain, Long Term Loss.* Observed at Uganda AIDS Commission, Kampala: Uganda, March 2010.

Young Empowered and Healthy. *“Something for Something” Love. Uncle Got a Few Moments of Pleasure and ... His Wife Found Out. Short Term Gain, Long Term Loss.* Observed at Uganda AIDS Commission, Kampala: Uganda, March 2010.

Would You Let This Man be with Your Teenage Daughter? So Why Are You with His? Observed at Uganda AIDS Commission, Kampala: Uganda, March 2010.

b) The AIDS Support Organisation (TASO)

Posters

The AIDS Support Organisation (TASO). *TASO Values.* Observed at The AIDS Support Organisation (TASO), Kampala: Uganda, March 2010.

The AIDS Support Organisation (TASO). *TASO Mission Statement.* Kampala: Uganda, March 2010.

The AIDS Support Organisation (TASO). *Commemoration of Christopher Kaleeba Day - “Strengthening Family Spirit to Defeat AIDS”, 23 January 2009.* Observed at The AIDS Support Organisation (TASO), Kampala: Uganda, March 2010.

Joint Clinical Research Centre (JCRC). *Tell Your Partner About Your HIV Status.* Observed at The AIDS Support Organisation (TASO), Kampala: Uganda, March 2010.

Joint Clinical Research Centre (JCRC). *Keep Your Dreams Alive – Choose Life – Take Your ARVs in the Right Amount at the Right Time Everyday*. Observed at The AIDS Support Organisation (TASO), Kampala: Uganda, March 2010.

Everybody Wins! World AIDS Day Quiz 2009. Uganda, Observed at The AIDS Support Organisation (TASO), Kampala: Uganda, March 2010.

The Uganda Network on Law, Ethics, HIV/AIDS (Uganda). *HIV/AIDS: Human Rights Now!!* Uganda, Observed at The AIDS Support Organisation (TASO), Kampala: Uganda, March 2010.

The Uganda Network on Law, Ethics, HIV/AIDS (Uganda). *HIV/AIDS: Human Rights Now!!* Uganda, Observed at The AIDS Support Organisation (TASO), Kampala: Uganda, March 2010.

The Ministry of Health STD/AIDS Control Programme and Strengthening HIV Control Training (SCOT). Uganda National HIV/AIDS Counselling Conference 2009. Observed at The AIDS Support Organisation (TASO), Kampala: Uganda, March 2010.

Ministry of Health. *One out of Every Twenty Couples Living Together in Uganda Has Different HIV Results. Do You? Test for HIV Together with Your Partner*. Uganda, Observed at The AIDS Support Organisation (TASO), Kampala: Uganda, March 2010.

Ministry of Health. *One out of Every Twenty Couples Living Together in Uganda Has Different HIV Results. Do You? Test for HIV Together with Your Partner*. Uganda, Observed at The AIDS Support Organisation (TASO), Kampala: Uganda, March 2010.

Ministry of Health. *Different HIV Test Results? Protect Your Partner from HIV. Start by Testing Together for HIV*. Uganda, Observed at The AIDS Support Organisation (TASO), Kampala: Uganda, March 2010.

National Palliative Care Association. 3rd APCA Conference – *Palliative Care in Africa – Creativity in Practice*, 15-17 September 2010. Uganda, Observed at The AIDS Support Organisation (TASO), Kampala: Uganda, March 2010.

XVIII International AIDS Conference. *See You in Vienna*. Uganda, Observed at The AIDS Support Organisation (TASO), Kampala: Uganda, March 2010.

Joint Clinical Research Centre (JCRC). *Choose Life*. Uganda, Observed at The AIDS Support Organisation (TASO), Kampala: Uganda, March 2010.

World AIDS Day. *Universal Access and Human Rights – Access is My Right, Testing My Responsibility*, 2009. Uganda, Observed at The AIDS Support Organisation (TASO), Kampala: Uganda, March 2010.

Other Wall Materials

AIDS International Memorial Day. *Candlelight Memorial Observance 2009*. Leaflet. Observed at The AIDS Support Organisation (TASO), Kampala: Uganda, March 2010

The AIDS Support Organisation (TASO). *TASO Training Centre, Course Calendar 2010*. Document. Uganda, Observed at The AIDS Support Organisation (TASO), Kampala: Uganda, March 2010.

I Have The Right to HIV Prevention Tools that Work for Me...Where Are the Female Condoms? Leaflet. Uganda, Observed at The AIDS Support Organisation (TASO), Kampala: Uganda, March 2010.

World AIDS Campaign. *I am One of the Million Tested for HIV*. Leaflet. Uganda, Observed at The AIDS Support Organisation (TASO), Kampala: Uganda, March 2010.

c) Billboards

Good Life and One Love Campaigns. *“Mummy is Sick Most of the Time Because of the Sexual Network.”* Observed at Kampala: Uganda, March 2010.

Its Within Your Power to Remain Faithful. Go Red – For Fidelity. Be Reliable, Exceptional & Dependable. 5 copies. Observed at Kampala: Uganda, March 2010.

Good Life and One Love Campaigns. *“These Empty Streets Are All We Have Because of the Sexual Network.”* Observed at Kampala: Uganda, March 2010.

Good Life and One Love Campaigns. *“Mummy is Sick Most of the Time Because of the Sexual Network.”* Observed at Kampala: Uganda, March 2010.

Good Life and One Love Campaigns. *The Sexual Network Does Not Stop with You! HIV Spreads Like Wild Fire in Sexual Networks!* January 2010. Observed at Kampala: Uganda, March 2010.

Ministry of Health. *Different HIV Test Results? Protect Your Partner from HIV. Start by Testing Together for HIV.* Observed at Kampala: Uganda, March 2010.

Ministry of Health. *Married Couples Are More Likely to Have HIV. Test for HIV Together with Your Partner.* Observed at Kampala: Uganda, March 2010.

We Take Care of Our Lives. We Know Our HIV Status. How About You? Stay HIV Negative – Stay Healthy. Observed at Kampala: Uganda, March 2010.

I Am A Leader and a Father. I Get Tested for HIV Regularly. Stay HIV Negative. Stay Healthy. Observed at Kampala: Uganda, March 2010.

d) National Community of Women Living with HIV/AIDS (NACWOLA)

Wall Materials

Women Fair Worse in Election Laws. Document. Observed at National Community of Women Living with HIV/AIDS (NACWOLA) Office, Kampala: Uganda, March 2010.

Play Your Part! A 9-Step Guide for Responsible and Proactive Citizen Action in the Electoral Process. Leaflet. Observed at National Community of Women Living with HIV/AIDS (NACWOLA) Office, Kampala: Uganda, March 2010.

National Community of Women Living with HIV/AIDS (NACWOLA). *NACWOLA's Philosophy.* Framed Poster. Observed at National Community of Women Living with HIV/AIDS (NACWOLA) Office, Kampala: Uganda, March 2010.

4) Ghana

a) Society of Women Against AIDS in Africa (SWAA)

Posters

Academy for Educational Development. *Strengthening HIV and AIDS Response Partnership – the Remarkable Text Me! Flash Me! Helpline Pilot Counsellors.* Observed at Society for Women and AIDS in Africa (SWAA), Accra: Ghana, February 2010.

Academy for Educational Development. *Strengthening HIV and AIDS Response Partnership Text Me! Flash Me! Helpline Program – FSW Knowledge and Behaviors – Information Sheet for Helpline Counsellors.* Observed at Society for Women and AIDS in Africa (SWAA), Accra: Ghana, February 2010.

World Aids Campaign. *Empower – Stop AIDS. Keep the Promise.* Poster. Observed at Society for Women and AIDS in Africa (SWAA), Accra: Ghana, February 2010.

World Aids Campaign. *Deliver – Stop AIDS, Keep the Promise.* Poster. Observed at Society for Women and AIDS in Africa (SWAA), Accra: Ghana, February 2010.

World Aids Campaign. *Have You Heard Me Today? No Sex, No School.* Observed at Society for Women and AIDS in Africa (SWAA), Accra: Ghana, February 2010.

World Aids Campaign. *Have You Heard Me Today? No Respect, No Hope.* 3 copies. Observed at Society for Women and AIDS in Africa (SWAA), Accra: Ghana, February 2010.

Society of Women Against AIDS in Africa (SWAA). *Use Condoms Correctly and Consistently – Prevent HIV/STI Infection.* Poster with samples of male and female condoms. Observed at Society for Women and AIDS in Africa (SWAA), Accra: Ghana, February 2010.

Who Are You to Judge? People Living with HIV are Just Like You. Observed at Society for Women and AIDS in Africa (SWAA), Accra: Ghana, February 2010.

Japan International Cooperation Agency. *Its Cool! Use Condoms – Wear it Always – Play it Safe.* Observed at Society for Women and AIDS in Africa (SWAA), Accra: Ghana, February 2010.

Newspaper Articles

Let's Promote Use of Condom Among Men, Women. Observed at Society for Women and AIDS in Africa (SWAA), Accra: Ghana, February 2010.

Make HIV/AIDS a Campaign Issue – SWAA. Observed at Society for Women and AIDS in Africa (SWAA), Accra: Ghana, February 2010.

24,000 Ghanaians Get HIV Yearly – Youth Form Majority, SWAA Expresses Concern. Observed at Society for Women and AIDS in Africa (SWAA), Accra: Ghana, February 2010.

UNAIDS Donates Equipment to Women's Society. SWAA Expresses Concern. Observed at Society for Women and AIDS in Africa (SWAA), Accra: Ghana, February 2010.

Be Part of the 'Know Your HIV Status Campaign'. Observed at Society for Women and AIDS in Africa (SWAA), Accra: Ghana, February 2010.

Daily Graphic. *HIV Infections – Death Rate Falls*, November 25, 2009. Observed at Society for Women and AIDS in Africa (SWAA), Accra: Ghana, February 2010.

Daily Graphic. *Stand Up to Violence Against Women*, November 26, 2009. Observed at Society for Women and AIDS in Africa (SWAA), Accra: Ghana, February 2010.

Daily Graphic. *S. Africa to Treat All Babies with HIV*, December 2, 2009. Observed at Society for Women and AIDS in Africa (SWAA), Accra: Ghana, February 2010.

Daily Graphic. *Cervical Cancer Vaccine Available*, November 17, 2009. Observed at Society for Women and AIDS in Africa (SWAA), Accra: Ghana, February 2010.

Daily Graphic. *Protect Yourself Against HIV – Dr El-Adas Tells Youth*, December 2, 2009. Observed at Society for Women and AIDS in Africa (SWAA), Accra: Ghana, February 2010.

Daily Graphic. *WHO Changes Advice on HIV Drugs*, December 1, 2009. Observed at Society for Women and AIDS in Africa (SWAA), Accra: Ghana, February 2010.

Other Wall Materials

Ghana AIDS Commission. *2010 Calendar*. Calendar. Observed at Society for Women and AIDS in Africa (SWAA), Accra: Ghana, February 2010.

Do You Know Your HIV Status? Leaflet. Observed at Society for Women and AIDS in Africa (SWAA), Accra: Ghana, February 2010.

Stop AIDS. Love Life Campaign. *Abstain (from Sex) or Be Faithful (Together) or Condom Use (Everytime) – The Choice is in Your Hands*. Signage. Observed at Society for Women and AIDS in Africa (SWAA), Accra: Ghana, February 2010.

Society for Women and Aids in Africa (SWAA). *Address, Telephone number, E-mail and Website*. Signage. Observed at Society for Women and AIDS in Africa (SWAA), Accra: Ghana, February 2010.

b) Women United Against AIDS in Africa (WUAAG)

Posters

Protect Your Dream – Abstain from Sex, Focus on Your Studies to Achieve Your Dream. Observed at Women United Against AIDS in Ghana (WUAAG) Office, Accra: Ghana, February 2010.

Protect Your Dream – Avoid Unprotected Sex, Stay Unaffected to Achieve Your Dream. Observed at Women United Against AIDS in Ghana Office (WUAAG) Office, Accra: Ghana, February 2010.

Black Coalition for AIDS Prevention. *What Else Isn't He Telling You?* Poster. Observed at Women United Against AIDS in Ghana (WUAAG) Office, Accra: Ghana, February 2010.

Black Coalition for AIDS Prevention. *I Was Born with HIV/AIDS*. Poster. Observed at Women United Against AIDS in Ghana (WUAAG) Office, Accra: Ghana, February 2010.

Black Coalition for AIDS Prevention. *Not Your Panties?* Poster. Observed at Women United Against AIDS in Ghana (WUAAG) Office, Accra: Ghana, February 2010.

Black Coalition for AIDS Prevention. *It's Just You and Me Now*. Poster. Observed at Women United Against AIDS in Ghana (WUAAG) Office, Accra: Ghana, February 2010.

Black Coalition for AIDS Prevention. *Trust Me Baby I'll Pull Out*. Poster. Observed at Women United Against AIDS in Ghana (WUAAG) Office, Accra: Ghana, February 2010.

Black Coalition for AIDS Prevention. *HIV/AIDS Last Longer Than 8 Months*. Poster. Observed at Women United Against AIDS in Ghana (WUAAG), Accra: Ghana, February 2010.

"Different But Equal" is a Lie – Affirmative Action Must Not Die. Poster. Observed at Women United Against AIDS in Ghana (WUAAG) Office, Accra: Ghana, February 2010.

Protect Your Dream – Know Your Facts. Poster. Observed at Women United Against AIDS in Ghana (WUAAG) Office, Accra: Ghana, February 2010.

Newspaper Articles

Daily Graphic. *You Have Human Rights – Women Living with HIV Told*, September 27, 2007. Newspaper Article. Observed at Women United Against AIDS in Ghana Office (WUAAG) Office, Accra: Ghana, February 2010.

Daily Graphic. *Love and Support, Not Stigmatisation For People Living with HIV/AIDS*, January 30, 2007. Newspaper Article. Observed at Women United Against AIDS in Ghana (WUAAG) Office, Accra: Ghana, February 2010.

Daily Graphic. *Women’s Group Respond Positively to HIV/AIDS*, September 19, 2006. Newspaper Article. Observed at Women United Against AIDS in Ghana (WUAAG) Office, Accra: Ghana, February 2010.

Por de la Malaltia, del Rebuig I de la Humiliacio. In Catalan. *Fear of the Disease, and Rejection of Humiliation* [Translated title]. Newspaper Article. Observed at Women United Against AIDS in Ghana (WUAAG) Office, Accra: Ghana, February 2010.

c) National Association of People Living with HIV/AIDS (NAP-GHANA)

Posters

Action Aid Ghana. *Do You Take This Man to be Your Lawfully Wedded Husband...Till Death Do Your Part? I Don’t!* Poster. Observed at National Association of People Living with HIV/AIDS (NAP-GHANA), Accra: Ghana, February 2010.

Forum Virtual - Adolescentes Y Jovenes. In Spanish. *Virtual Forum – Adolescents and Youth* [Translated Title]. Leaflet. Observed at National Association of People Living with HIV/AIDS (NAP-GHANA), Accra: Ghana, February 2010.

Pan American Health Organisation. *Discrimination – If it Doesn’t Raise Your Blood Pressure, Get a Checkup*. Leaflet. Observed at National Association of People Living with HIV/AIDS (NAP-GHANA), Accra: Ghana, February 2010.

Vientiane Statement of Commitment on the Greater Involvement and Empowerment of People Living with HIV, Vientiane, Lao PDR, 9 May 2008. Poster. Observed at National Association of People Living with HIV/AIDS (NAP-GHANA), Accra: Ghana, February 2010.

d) Billboards

Billboards Observed in February 2010

Customs Excise and Preventive Service. *“Officer! Know Thy Status” Voluntary HIV Testing – A Wise Decision*. Billboard. Observed at Accra: Ghana, February 2010.

Joint-Regional HIV AIDS Project in the Abidjan-Lagos Transport Corridor. *Traveller, Never Forget. AIDS Cross Borders, Let's Prevent It!*. Billboard. Observed at Accra: Ghana, February 2010.

Projet Régional Commun de Prévention et de Prise en Charge des IST/VIH/SIDA le Long du Corridor de Migration Abidjan-Lagos. *Voyageur, N'oublie Jamais. Le Sida n'a pas de frontières, protège toi!* In French. *Traveller, Never Forget. AIDS Cross' Borders, Let's Prevent It!* [Translated title]. Billboard. Observed at Accra: Ghana, February 2010.

Know Your HIV Status Campaign. Adabraka Polyclinic. *This is Your Opportunity to Know Your HIV Status. Visit Us for Free Counselling and Testing Now*. Billboard. Observed at Accra: Ghana, February 2010.

GWCL/AVRL HIV/TB Workplace Program. *Live to Enjoy Water – Know Your HIV/TB Status Today*. Billboard. Observed at Accra: Ghana, February 2010.

AIDS Spreads Through Sex. To Protect Yourself, Have an Uninfected Sexually-Faithful Partner for Life, Use a Condom Properly Every Time You Have Sex. Remember. It's Not Necessary to Die of AIDS. Billboard. Observed at Accra: Ghana, February 2010.

HIV/AIDS. You Can Prevent Your Baby from HIV Infection, Get Tested; Your Baby May be Protected. Know Your Status. It's Cool to Get Tested. Billboard. Observed at Accra: Ghana, February 2010.

HIV/AIDS is Real – Abstain from Sex and Unprotected Sex and Achieve Your Goal. Billboard. Observed at Accra: Ghana, February 2010.

HIV/AIDS is Preventable – Just as Fire Is – HIV/AIDS and TB Voluntary – Counselling, Testing and Treatment. Billboard. Observed at Accra: Ghana, February 2010.

Datoyili Women's Coalition and Ghana AIDS Commission Project. *Say No to Sex. Virgin Power! Avoid HIV/AIDS*. Billboard. Observed at Tamale: Ghana, February 2010.

Woman Take Control! AIDS is Real. Yei Akundɔŋ Nɛ, Mmaa Kondɔm Nie. In English and Twi. Billboard. Observed at Tamale: Ghana, February 2010.

5) Regional Southern Africa

a) AIDS and Rights Alliance for Southern Africa (ARASA)

Posters

International Council of Nurses (ICN) *...and Enjoy My Right to be Loved, and to Love Others*. Poster. Observed at AIDS and Rights Alliance for Southern Africa (ARASA), Windhoek: Namibia, August 2010.

International Council of Nurses (ICN). *Uphold the Rights of Women by Ending Violence Against Them*. Poster. Observed at AIDS and Rights Alliance for Southern Africa (ARASA), Windhoek: Namibia, August 2010.

International Council of Nurses (ICN). Access My Right to Information to Keep Me Safe from HIV Infection, and My Right to Support to Keep Me Secure. Poster. Observed at AIDS and Rights Alliance for Southern Africa (ARASA), Windhoek: Namibia, August 2010.

International AIDS Society (IAS) and AIDES. *Stop HIV. Not People Living with AIDS*. Observed at AIDS and Rights Alliance for Southern Africa (ARASA), Windhoek: Namibia, August 2010.

AIDS and Rights Alliance for Southern Africa (ARASA). *The Right to Health is Worth More than Gold*. Observed at AIDS and Rights Alliance for Southern Africa (ARASA), Windhoek: Namibia, August 2010.

AIDS and Rights Alliance for Southern Africa (ARASA). *No Testing without Respect for Human Rights*. Observed at AIDS and Rights Alliance for Southern Africa (ARASA), Windhoek: Namibia, August 2010.

AIDS and Rights Alliance for Southern Africa (ARASA). *Regional Partnerships for Universal Access*. Observed at AIDS and Rights Alliance for Southern Africa (ARASA), Windhoek: Namibia, August 2010.

AIDS and Rights Alliance for Southern Africa (ARASA). *No to Forced Sterilisation!* Observed at AIDS and Rights Alliance for Southern Africa (ARASA), Windhoek: Namibia, August 2010.

Other Materials

Ghana AIDS Commission. *AIDS is Not Over ... the Time to Act is Now! 2009 Calendar*. Calendar. Observed at Women United Against AIDS in Ghana (WUAAG) Office, Accra: Ghana, February 2010.

b) Southern African AIDS Information Dissemination Service (SAfAIDS)

Posters

Africa Goal, Southern African AIDS Information Dissemination Service (SAfAIDS), Government of Canada. *There is a Better Way to Protect Yourself: HIV Know the Score*. Poster. Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Ministry of Health, Government of Zimbabwe et al. *Zimbabwe Cares: No Woman Should Die While Giving Life*. Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Southern African AIDS Information Dissemination Service (SAfAIDS). *SAfAIDS Journey June 30 2010 – July 31 2015*. Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Southern African AIDS Information Dissemination Service (SAfAIDS). *Priority 1: Combination Prevention*. Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Southern African AIDS Information Dissemination Service (SAfAIDS). *Priority 2: Gender Equality and Women's Rights*. Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Southern African AIDS Information Dissemination Service (SAfAIDS). *Priority 3: Linking HIV and TB with SRH and R [Sexual and Reproductive Health and Rights], PMTCT [Prevention of Mother to Child Transmission] and MCH Maternal and Child Health*. Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Southern African AIDS Information Dissemination Service (SAfAIDS). *Priority 4: Mitigating the Impacts of HIV and Climate Change*. Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Southern African AIDS Information Dissemination Service (SAfAIDS). *Priority 5: Policy and Advocacy*. Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Southern African AIDS Information Dissemination Service (SAfAIDS). *Priority 6: Documentation of Best Practices and Operational Research Requirements*. Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Southern African AIDS Information Dissemination Service (SAfAIDS) et al. *Africa Wins Every Time You Keep Your Promise! Abuja 15% NOW!* Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS) et al. "Don't Be Negative About Being Positive." English version. Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS) et al. "Don't Be Negative About Being Positive." Zulu version. Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Southern African AIDS Information Dissemination Service (SAfAIDS) et al. *Is a Hangover the Only Thing You Have to Worry About in the Morning? (Featuring a Man)* Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Southern African AIDS Information Dissemination Service (SAfAIDS) et al. *Is a Hangover the Only Thing You Have to Worry About in the Morning? (Featuring a Woman)* Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Southern African AIDS Information Dissemination Service (SAfAIDS) et al. *Kids for Real (1)*. Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Southern African AIDS Information Dissemination Service (SAfAIDS) et al. *Kids for Real (2)*. Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Southern African AIDS Information Dissemination Service (SAfAIDS). *Distribution Hubs*. Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Southern African AIDS Information Dissemination Service (SAfAIDS). *Exhibitions*. Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Southern African AIDS Information Dissemination Service (SAfAIDS). *I Enjoy Supporting My Partner and Promoting Her Rights... Do You?* Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Southern African AIDS Information Dissemination Service (SAfAIDS). *Maternal Child Health the CARMMA launch (Campaign on Accelerating Reduction of Maternal Mortality)*. Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Thandie Asks About HIV. Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Other Materials

Southern African AIDS Information Dissemination Service (SAfAIDS). *Person Seated Next to a Poster Reading: Africa WINS! Every Time YOU Prevent HIV!* Photograph. Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Southern African AIDS Information Dissemination Service (SAfAIDS). *Two People With Vuvuzelas Standing Next to a Cardboard Cut-out of Obama Wearing an 'Africa Wins' Campaign T-shirt*. Photograph. Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Displays

Southern African AIDS Information Dissemination Service (SAfAIDS). *Gender Culture and HIV*. Display. Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Southern African AIDS Information Dissemination Service (SAfAIDS). *Africa Wins Everytime You Prevent HIV*. Display consisting of: 4 coasters, 2 branded soccer balls, 2 bags, 4 vuvuzelas, 3 bumper stickers. Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Southern African AIDS Information Dissemination Service (SAfAIDS). *Advocacy and Policy*. Display. Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Southern African AIDS Information Dissemination Service (SAfAIDS). *CBVs* [Community Based Volunteers]. Display. Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Southern African AIDS Information Dissemination Service (SAfAIDS). *ICTs* [Information and Communications Technology] *and Media*. Display. Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Southern African AIDS Information Dissemination Service (SAfAIDS). Display Table Consisting of: 1 branded bag, 6 newsletter editions, 1 Annual Report, 4 sets of coasters, 9 booklets. Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Stickers

Africa's Prosperity Tomorrow Achieving MDGs [Millennium Development Goals] *4 and 5*. Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Southern African AIDS Information Dissemination Service (SAfAIDS) et al. *Ke nako* [Translate title *It's Time*] *Abuja 15% Now*. Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Southern African AIDS Information Dissemination Service (SAfAIDS) et al. *Every One Child Should Survive*. Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Southern African AIDS Information Dissemination Service (SAfAIDS) et al. *No Woman Should Die While Giving Life*. Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Southern African AIDS Information Dissemination Service (SAfAIDS) et al. *2010: Time Out!! Beyond the Pen, Universal Access – MDGs [Millenium Development Goals] – Abuja 15% - Maputo Plan of Action*. Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Southern African AIDS Information Dissemination Service (SAfAIDS) et al. *Everyone Has a Role to Play*. Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Southern African AIDS Information Dissemination Service (SAfAIDS) et al. *Africa's Prosperity Tomorrow Achieving MDGs [Millenium Development Goals] 4 and 5*. Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Southern African AIDS Information Dissemination Service (SAfAIDS) et al. Prevention and TB Display Consisting of: 3 booklets, newsletter, one book and one bag. Observed at Southern African AIDS Information Dissemination Service (SAfAIDS), Pretoria, Gauteng, South Africa, August 2010.

Erratum

In light of changed circumstances and levels of risk since the time of research and submission the name of one interview participant was removed from this thesis in August 2017.