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# Inclusive Representation In Global Decision-Making Processes: Challenges Of Democracy, Sovereignty, And Liberatory Politics For Marginalized Groups

Laurel Dawn Sprague  
*Wayne State University,*

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**INCLUSIVE REPRESENTATION IN GLOBAL DECISION-MAKING PROCESSES:  
CHALLENGES OF DEMOCRACY, SOVEREIGNTY, AND LIBERATORY POLITICS FOR  
MARGINALIZED GROUPS**

by

**LAUREL SPRAGUE**

**DISSERTATION**

Submitted to the Graduate School

of Wayne State University,

Detroit, Michigan

in partial fulfillment of the requirements

for the degree of

**DOCTOR OF PHILOSOPHY**

2015

MAJOR: POLITICAL SCIENCE

Approved By:

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Advisor

Date

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## DEDICATION

*This is dedicated to my family: my partner, Elaine Dunlap, and my son, Chioke Bowden.*

*Thank you both.*

## ACKNOWLEDGEMENTS

I want to express my greatest appreciation to Brad Roth for your persistence, guidance, and support throughout the stages of this project. Every word read, every source recommended, every edit suggested, every proposition challenged, made this project so much more than it could have been. My gratitude also goes to my Committee Members: Sharon Lean, Philip Abbott, and Peter Hammer. This project took longer than any of us anticipated at its beginning. Your support and willingness to work with my drafts when I was able to send them, instead of when might have been more convenient for you, are deeply appreciated. To have the support of four professors for whom I have such great respect is more encouraging than I can say. Thank you also to Ronald Brown, for making time for deep and important conversations with a new graduate student and for embodying an approach to scholarship based in commitment to social justice. I learned more about research in our informal conversations than in any formal training.

I also want to acknowledge and thank the AIDS activists, feminists, lesbian and gay liberationists, transgender rights advocates, and committed anti-racists – those here and those who have passed on to the other side - who have been my companions, my friends, and my support. I have been honored to be part of a community of people who, time and again, have refused to accept treatment that diminishes our common humanity and who have insisted that the right response to disparaging treatment is dignity, humor, resistance, and resolve. My heartfelt thanks go to Patrick Welsh who showed by example that one could talk to even the most angry and prejudiced people as if holding a conversation with a dear friend and to Derrick Anderson who taught me to keep loving and keep fighting.

## PREFACE

My commitment to this project arises from the joining together of two streams of experience that have deeply influenced me. One stream is the academic training and mentoring that I have received in political theory, particularly in the philosophies of human rights, democracy, civil society engagement, and political representation. The other stream is my professional and personal engagement since the 1990s with grassroots, national, and international networks of people living with, affected by, and concerned about, HIV and AIDS. This engagement has included work on HIV-related stigma and discrimination with networks of people living with HIV in Sub-Saharan Africa, Central and Eastern Europe, and North America, as well as with the Joint United Nations Programme on HIV and AIDS (UNAIDS), USAID, and international research institutions, such as the International Center for Research on Women. My understanding of the issues facing marginalized groups, and the challenges to participation by those most subordinated within these groups, has been shaped by participation in strategic and advocacy planning sessions on the inclusion of people living with HIV and members of marginalized groups within Canadian and United States' provincial, state, and regional organizations and, at the international level, with the Global Network of People Living with HIV, the ATHENA network and other collaborations among women's health advocates, and the International Community of Women Living with HIV.

My attention to Indigenous Peoples' organizing arose later as I began to work more closely with Native Americans and Aboriginal Canadians living with HIV, who were advocates for native peoples in both fields. My understanding of the effects of exclusion on Indigenous Peoples deepened in 2013, when I attended a presentation to the U.S.

Presidential Advisory Council on HIV and AIDS on the situation of Native Americans and HIV. This presentation, by Dr. Katrina Walters and Harlan Pruden taught me to look at intergenerational trauma, fears that one's community will cease to exist, vulnerabilities within States for groups whose existence challenges the logic of the State, and the intersections of vulnerabilities that Indigenous Peoples who are also HIV-positive face.

Midway through this dissertation project, in 2014, I became more deeply involved in the issues I was studying when I was selected to represent North American civil society organizations on the UNAIDS Programme Coordinating Board (the Board of Directors for UNAIDS). My appointment as one of the two delegates representing North American has greatly sensitized me to the challenges of representing a large, diverse community of affected groups who face multiple intersecting vulnerabilities and stigmas, including those based on HIV-status and those based on sexual and gender orientation, race, class, and sex. All of these serve as forces for exclusion, albeit in different forms for different groups, from meaningful participation in decision-making processes.

There are some experiences that change us forever. For me, those experiences come from two directions: tremendous acts of dignity and courage in the face of mistreatment, and deep analyses that expose systems of power, meant to be invisible, that serve to trap and limit us. It has been my good fortune to be surrounded by a disproportionate number of people able to engage in both of these activities. This work can never be solely professional nor solely personal for me. I believe this is a strength.

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## CHAPTER 1 INTRODUCTION

What should be the role of unelected civil society members in global decision-making? More specifically, how much power should disliked or marginalized social groups have to influence decisions that have a disproportionately weighty effect on their wellbeing? Does purposeful inclusion of marginalized groups increase the democratic nature of political processes by providing a voice to those otherwise excluded? Or does it unjustifiably limit the ability of nations and national majorities to self-determine the policies under which they live?

Consider three examples:

In Geneva, the Joint United Nations Programme on HIV/AIDS (UNAIDS) makes governance and policy decisions through its governing body—the Programme Coordinating Board (PCB). Five representatives from civil society sit on the PCB alongside 22 representatives of states and the eleven UN cosponsors that make up the Joint Programme. While the civil society representatives do not have voting rights on the board, decisions are made by consensus, providing civil society organizations with the power to suggest, negotiate, and even potentially to block, decisions.

In New York City, the Permanent Forum on Indigenous Issues for the United Nations (Permanent Forum) provides recommendations and engages in advocacy efforts for the inclusion of issues important to Indigenous peoples throughout the UN system. The governing board of the Permanent Forum is composed of eight government appointed representatives and eight representatives selected by Indigenous communities from different regions of the world.

In Kingston, Jamaica, the national body charged with creating a national HIV/AIDS strategy and determining the roll out of funds from the Global Fund to Fight AIDS, Tuberculosis, and Malaria is chaired by an openly gay man from an organization dedicated to the health and rights of “men who have sex with men, sex workers, people who use drugs, orphans and other children made vulnerable by HIV, migrant populations, ex-prisoners, and youth in especially difficult circumstances” (Caribbean Vulnerable Communities 2015). This influential position is held despite Jamaican sodomy and indecency laws criminalizing gay relationships. The Chairperson was selected to serve on this decision-making body, not by the government, but through elections held by Jamaican civil society organizations. The members of the decision-making body then chose their leadership, selecting a member from the government and one from academia as vice-chairs. Similar arrangements, established to meet Global Fund funding criteria, are found among other global-fund recipient countries worldwide.

These are but a few examples of the ways in which non-elected civil society representatives have gained influence on matters of global importance. Further, these civil society representatives come from groups historically disadvantaged within their own countries. Indeed, their domestic marginalization is the very reason for their inclusion in global decision-making processes. The work done at global levels by the bodies in which these civil society representatives serve is felt at national levels, directly in the case of the Global Fund, and indirectly through the United Nations. The result is that groups with little to no influence on national policies through traditional domestic political processes play a role in shaping both global norms and national policies. This current situation creates a compelling challenge in which two highly valued aspects of just democratic governance are

pitted against one another: the inclusion of a political voice for those who are affected by policies but are, otherwise, excluded from meaningful participation in the crafting of these policies versus the widely-held principle that legitimate public policies are those that have the support of the majority – or some kind of institutionally-structured plurality - of a country's citizens.

For clarity, throughout this project, the term civil society refers to associations of people that are voluntary, non-governmental (not created or controlled by the government), and outside of the business sector. In this definition, civil society includes associations that are new and loosely organized as well as those with strong, ongoing organizational structures. This definition does not distinguish between associations created for reactionary, or exclusionary, purposes and those seeking to promote greater inclusion. Both groups may well contain a combination of inclusive and exclusive goals. For example, they may consist of people who are excluded from decision-making themselves and seeking inclusion while simultaneously seeking exclusion of specific others. To exclude more reactionary groups from the analysis on the basis that their goals are un-civil would be to misunderstand the nature of contestation within societies. Groups historically excluded from power -- such as the poor; racial or ethnic minorities, particularly those whose ancestry stems from low and middle-income regions; or women seeking full equality -- must contend within civil society with reactionary, un-civil groups that are devoted to their exclusion. Those on both sides frequently seek the exclusion of the other: reactionary groups in favor of the status quo and marginalized groups seeking greater justice than the status quo offers.

### ***Statement of the problem***

The central aspect of political equality is to have a voice in decision-making processes whereby people, or their representatives, have a reasonable chance of shaping the decisions that affect their lives (or, in cases of direct democracy, individuals have a reasonable chance of affecting decisions that affect their lives). Without this voice, people remain politically as children under the guardianship of others. Others make decisions for them; and neither they, nor their chosen representatives, make decisions for themselves. Political majorities or other decision-makers may view them sympathetically -- as “good children”-- or unsympathetically -- as “bad children”. Nonetheless, they are treated as children and barred from political decision-making on their own behalf.

The path of democratic progress is one of movement toward the recognition of political adulthood for increasing numbers of people. Children, politically speaking, are those for whom others make decisions. Adults, politically speaking, are those perceived by themselves and others in the political community as having emerged childhood to take their station in the community as equals in the practice of self-government. In 1775, in his “Speech on Conciliation with the Colonies,” Edmund Burke expressed the following:

Perhaps we might wish the colonists to be persuaded, that their liberty is more secure when held in trust for them by us (as their guardians during a perpetual minority) than with any part of it in their own hands.

People have struggled to take part in the practice of self-governance “in their own hands” through the multiple battles for suffrage that ultimately extended the franchise in Western democracies to non-property owners, women, and racial, ethnic, and national minorities.

What is the intended result of these struggles? The equal ability for each person to influence legislation and to participate in the creation of the laws and policies that affect

them. However, this equality has never been realized. Some groups of citizens are, and have been, persistently unable to influence political decisions that affect them. Simply having an equal vote does not ensure meaningful and effective representation, as is illustrated by the many minority members in the U.S. who can vote in every election for their entire lives and never see a candidate whom they see as representing their interests win an election (Ely 1980). As a result, these groups find themselves caught in a condition of political childhood.

At the same time, global organizations and institutions are struggling to identify good practices for representation of marginalized peoples. This struggle takes place within, and responds to, a global context in which there is an increasing sense that global human rights norms can apply to realms of human life previously considered to be the sole purview of national governments, such as protection of the environment and the rights of people with disabilities or members of Indigenous groups (Cohen and Rai 2000, Nagel 1999). At the same time, the question of whether a human right to democratic participation exists has emerged in public consciousness and debates among political theorists (Benhabib 2011, Fox 2000, Franck 2000, Roth 2000). The debates focus on a right to participation at a national level; however, they are part of a larger movement in which human rights language is used to make claims for inclusion.

The convergence of these conditions has created an impetus within non-governmental and international bodies to turn their attention inward toward their own representation processes as well as outward to offer guidelines for appropriately inclusive processes to global institutions. This combination of events gives rise to a question that is simply put, yet is of critical importance for modern global governance: Who should

participate in global decision-making processes? Traditionally, the answer has also been quite simple: states, through their representatives, were charged with this right and responsibility. However, the question has become particularly acute in the current context in which, first, discussions about a right to democracy are gaining increased currency and awareness, and, second, many of the contemporary issues of global governance address situations within which national governments fail to adequately protect or consider their most marginalized populations. In response, the United Nations system has brought representatives of vulnerable and marginalized populations into decision-making processes, placing them alongside the representatives of states. Similarly, other international bodies and non-governmental organizations have devised various mechanisms for including representatives of key populations in their own governance and decision-making processes (Warren & Castiglione 2004).

However, this inclusion in global processes, while laudable for its commitment to the dignity of marginalized peoples, requires attention to both the processes and the guiding assumptions that animate it. In terms of processes, marginalized populations, in many cases, cannot be represented according to traditional models. Their constituencies may cross multiple geographical borders, as well as social, religious, and language groups. They may not be organized into defined political units able to hold elections and hold representatives accountable. Indeed, some groups are criminalized domestically which makes political organizing difficult (one example is the status of lesbians and gay men in the 78 countries which criminalize homosexuality). These challenges create an almost insurmountable barrier to representation of marginalized populations in the way that legitimate representation has been traditionally conceived – as requiring representatives



to be intentionally selected by their constituents and to be accountable to them, in an open contest in which information is freely available and all members of the represented group are able to participate without fear of reprisals (Pitkin 1967; Dahl 1989). To determine legitimate processes requires new ways of thinking about representation within the context of global realities.

Beyond the examination of processes, the assumptions that drive the movement toward inclusion require attention. These assumptions have not, to date, been fully specified by either proponents or opponents of these global efforts at inclusive representation, but four fundamental assumptions can be identified:

- First, that people ought to have a voice in the decisions that affect the conditions of their lives,<sup>1</sup> and, correspondingly, that *groups* of people ought to have meaningful involvement in decision-making about issues that have a distinct impact on the members of the group;
- Second, that inclusion within global governance fora is the proper solution for groups that are marginalized domestically and that have important stakes in particular political decisions;
- Third, that representatives of marginalized groups generally must, themselves, be members of the group (descriptive representatives, as Pitkin (1967) and subsequent scholars have named them); and

---

<sup>1</sup> Young (2006) highlights the importance of global fora for providing this voice. She argues that the kinds of decisions on which groups ought to have a voice are those that “affect one’s life conditions for self-development and self-determination” (1).

- Fourth, that inclusion of representatives of marginalized groups is an unqualified good in terms of democratic practices, globally and domestically, and poses no risk of harm.

The goal of this project is to conduct a close analysis of the principles of inclusive representation of marginalized groups in global decision-making processes, both as analyzed by political theorists and as currently practiced in global institutions. From this foundation, this project offers a framework for inclusive global representation that meets democratic conditions for participation and voice of those most affected by specific issues, and that does so in ways that reduce domination, while attending to challenging concerns about the interests of majorities, state sovereignty, and unintended consequences that could harm the group or those most marginalized within the group.

### ***Democracy***

Inclusion of non-elected civil society representatives, especially those from marginalized groups, raises a concern for normative democratic theory of how to understand the competing democratic tensions created by this inclusion: the democratic impulse to increase access to decision-making for those who historically have been kept out of positions of power versus the democratic focus on the enactment of public policies that have the support of national majorities. The fundamental questions for democratic theory are whether governmental policies that are enacted by democratic states and that affect marginalized communities are legitimate in democratic terms when there is no effective way for these communities to affect the decision-making (that is, the policies affect but are not affected by the minority) and, conversely, whether governmental policies

that address the needs of marginalized groups are legitimate if they appear to contradict the political interests or wishes of the majority of the population.

One's conceptualization of the meaning of democracy will shape the answer to these questions. Democratic theorists differ in their emphasis the extent to which democracy is best defined by the processes adopted by a state (primarily voting) or whether the outcomes of these processes matter also. A brief explanation of each approach and its relevance for understanding the challenges of political representation of marginalized groups follows.

Works by Dahl (1989, 2006), Huntington (1991), and others describe representative democracy primarily, although not exclusively, in terms of processes, with Huntington directly advocating for a process-defined approach to democracy because of the way it sets up measurable criteria with which to evaluate a government's claims to be democratic. Approaches based on processes, like Huntington's, emphasize the importance of majority rule for legitimacy. As such, a process-defined approach to democracy raises substantial challenges to practices that place non-elected citizen representation in positions that affect domestic policies.

Other procedural approaches to democracy take a broader approach than majoritarianism. Certain social organizations, including those with persistent political minorities, ensure that majoritarianism does not translate into political equality. For example, when societies are segmented by language, religion, or ethnic divisions, then processes, such as consociational democracy (Lijphart 1969), that require consent from these different segments assure agreement across major social groups before laws or policies can be adopted. Lijphart (1969) describes consociational democracy as an

alternative structure for societies that are segmented such that cross-cutting consent is required for stability. However, Lijphart is clear that consociationalism works through the mutual agreement and accommodation of the elites who represent dominant social cleavages. As such, whether based on majoritarianism, super majorities, or consociationalism, these processes consistently leave out the marginalized groups that are the fundamental concern for this project.

Other democratic theorists place greater emphasis on the substantive outcomes of political processes. These scholars focus less on majoritarian aspects of democracy and more on the extent to which all members of the political community enjoy political equality. Roth (1995) argues that a normative approach that goes beyond the simple mechanics of voting is necessary for evaluating democratic progress. Ely (1980) argues that one must pay attention to those groups who are unable to participate equally in normal political processes, such as racial minorities who may find that racial animosity directed toward them by other citizens leaves them unable to form coalitions with other groups to press for their interests. For Dworkin (1999), the central aspect of democracy is whether the state shows equal concern for the good of all of its citizens.

While acknowledging the arguments for a process-driven definition of democracy, this project adopts Dworkin's approach and argues that the focus on majoritarianism that results from process-driven definitions is inadequate. Whether or not there is majority approval in any particular case, a political structure is not democratic in any meaningful sense of the term when some groups of people, who are otherwise full members of the political community, are consistently unable to exert any meaningful influence on policies that directly impact them. This is particularly true when a majority that will experience

few, or no, effects from the decisions that are made has the power to decide those policies. When some members of a political community are excluded *in practice* from effective participation in the decisions that concern them, they are not political equals, as required for a democratic process. Instead, they are, *in practice*, political wards, or children, of the majority who make decisions on their behalf. In Dworkin's (1999) words, they lack "moral membership" in their political community (102). I will discuss this concept of moral membership in the next chapter. At this point, it is important simply to note that Dworkin considers political decisions to be democratic only when they take place in the context of moral membership (1999, 102-105).

My concepts of political childhood and political adulthood build upon Agamben's (1998) conception of the "relations of ban." Agamben's "ban" refers to the hierarchical ordering of society by those with resources; an ordering within which some people are deemed inherently valuable and worthy of care and others are not. Those considered unworthy of care and concern are considered to be subject to the relations of ban. These are the groups with which this project is most concerned. Of particular relevance to discussions of democracy and political representation, those who have been banned are not excluded entirely from the state; they remain bound in a marginal position within the political system. Agamben describes the vulnerability of this existence on the margins, "He who has been banned is not, in fact, simply set outside the law and made indifferent to it but rather abandoned by it, that is, exposed and threatened" (Agamben 1998, 29). The struggle for inclusive representation is a struggle of people who have been denied full political adulthood and instead have been "abandoned," "exposed and threatened," by decisions that they have no effective hand in creating. When groups find that their own

governments persistently lack concern for their wellbeing then one result is that they have no voice to represent them in economic and political talks. In these cases, inclusive representation can serve as a liberatory practice, bringing political voice and stature to those who have been governed while excluded from governing.

### ***Representation***

Political theorists' conceptions of the kinds of interests within the *polis* that might require representation within political processes have undergone significant changes over time. When social contract theorists crafted their images of political communities, the ways in which processes of representation might work within in the governing structures of the social contract were ill defined at best. Instead, these theorists characterized political communities as largely unified by a common goal -- whether the goal was protection of human security (Hobbes, 1651), amelioration of the "inconveniences" of life without government (Locke, 1689), or the common good (Rousseau, 1762)--and thus devoted little attention or support to structures for channeling particular concerns through a system of representation.

The different interests that exist within a political community were Burke's (1792) focus in his writings on representation. However, for Burke, interests were narrowly conceived as business or economic interests. An examination of the problem of marginalized or minority populations emerged in the writings of J.S. Mill (1861) on proportional representation and deliberative assemblies. Mill recognized multiple interests within a citizenry, as exemplified by his focus on the existence of minorities within a community and what rights to participation they ought to have. However, Mill's

recommendations for greater inclusion and voice corresponded with his belief that the power of the deliberative body to make laws and policies must be limited.

A shift can be seen between the earlier ideas of minority groups or viewpoints that might need to be represented and current ideas. Modern political theorists have focused attention on the representation of women and on racial and ethnic minorities. This work follows Pitkin's (1967) close examination of different types of representatives and the identification of "descriptive representation," as one category. Descriptive representatives are those representatives who are selected because they are similar to their constituents on some, socially relevant, dimension. The idea of descriptive representation has been seen as highly relevant to concerns about representation of marginalized groups, with a substantial literature about legislative politics revolving around the question of whether marginalized populations are better represented by those who come from within the same population (Swain 1993, Thomas 1994, Phillips 1998, Lublin 1999, Mansbridge 1999). However, Young's (1990) discussion of the politics of difference presents a serious challenge to those who would suggest that a simple formula for descriptive representation will provide a political voice for those who are marginalized, drawing attention to the ways in which minorities within a minority group can be silenced when only the most privileged members of the group are expected to speak for all.

Emerging political theory on political representation attempts to address new issues of representation beyond the sphere of legislative politics. This literature is particularly relevant to a political theory of non-elective civil society representatives in the global sphere. Young (2002) argues for inclusion as an accountability mechanism for global organizations that otherwise lack transparency. Urbinati and Warren (2008) describe non-

electoral representation as “expan[ding] and pluraliz[ing] spaces of political judgment in today’s democracies” (403) and Held (2003) takes up the challenge of identifying conditions under which specific inclusion of marginalized groups in global decision-making processes is legitimate in democratic terms.

### ***Theoretical approach***

Feminist analysis provides the theoretical underpinnings of this study. Feminist theory illuminates two key approaches to the study of the relationship between marginalized groups, the states within which they live, and the global system: attention to human wellbeing through a consideration of those who are excluded or made invisible and an examination of the power dynamics within the predatory and the protective aspects of the state.

### *Attention to human wellbeing through consideration of that which is excluded or made invisible*

Feminist theory has, across time, offered an approach for interrogating both formal and informal political systems with the purpose of attending to the equality, liberation, and wellbeing of all members of a given *polis*. Concern for all members of a polis requires attention to those who might be missing from care. The feminist approach follows a rich tradition from Wollstonecraft’s ([1792] 1999) calls for attention to women’s “personhood” to Jaggar’s (1983) and Young’s (2005) illumination of the effects of women’s alienation from their bodies. While the feminist approach has consistently centered the situation of women and girls in analyses of political questions, newer feminist approaches have expanded the approach to other subordinated groups. Contemporary feminist theorists



have used understandings of marginalization to pay particular attention to the differences between those conceived of as “normal” and those who are considered “other” or invisible in political analyses: people with disabilities, lesbians, gay men, bisexuals, and transgendered people, racial and ethnic minorities, and those whose identities are at the intersections of two or more of these categories (Collins 1990, Kristeva 1982, Young 1990).

In this way, feminist theory’s distinct contribution to projects concerned with the conditions for human flourishing has been consistently to ask: Who is excluded? And then, to answer that question by exploring the situation of people in spaces labeled and restricted as private, such as the home or many of the traditional settings to which women have been assigned. Employing an approach based in a feminist commitment to human wellbeing means that one must attend to the inclusion of those excluded or made invisible within new global processes of representation.

*The state: predatory and protective*

Feminist theorists highlight the complex relationship between the state and marginalized groups when human rights are at issue. Early feminist writings about the role of political authority emphasized the power of the state to violate the rights of women, particularly in relation to denials of the right to vote and legal discrimination in favor of men in child custody and property rights (Report of the Woman's Rights Convention, Held At Seneca Falls, N.Y., July 19th and 20th, 1848; Wollstonecraft [1792] 1999). Over time, as formal equality for women has increased, feminist theorists have developed more nuanced analyses of the state (de Beauvoir 1949, Nussbaum 2000, Okin 1991). The calls for, and eventual adoption of, the Convention on Elimination of all forms of Discrimination against Women (CEDAW) in 1979, demonstrated a shift in recognition of the multiple ways in

which women face discrimination in daily activities and the responsibility of the state to address these.

The focus over the last decades has been on the state as a protective force against the multitude of private violations that women and girls face within families, communities, schools and social and religious organizations. However, there remain feminist voices that argue that the need for private space, protected from government intervention, continues to be essential for women's abilities to exist with dignity within any political system (Hirschmann 2003). As seen, different theorists highlight the importance of the state for guaranteeing the right to equal opportunities for participation and development ("positive liberty" in Berlin's (1969) terminology) and to ensuring that private actors do not prey on women or other marginalized groups with impunity. Other theorists focus on the right to be left alone and on the need to be free from predatory and invasive acts toward marginalized groups enacted by the state, itself (Berlin's "negative liberty"). Taken together, what these theorists demonstrate is that groups may need to simultaneously struggle for affirmative state action to ensure their rights are protected and for protections against state predation. I extend this work done by feminist theorists by claiming that an approach based in feminist theory will insist that one must hold in mind both the protective and predatory potential of the state when exploring questions of global and state justice. This kind of analysis allows an exploration of the kinds of political institutions that may be called for when neither abolishing nor strengthening the state is sufficient for ensuring justice for marginalized groups.

***Structure of the project***

This analysis of global processes for inclusive representation proceeds in four parts. The first part, Chapter 2, examines concerns in democratic terms about increasing the voice and influence of marginalized groups when these groups support policies that are opposed by majorities and then discusses support for this practice, also in democratic terms. The chapter concludes with an exploration of the conditions under which inclusive representation might strengthen democratic practices. The second part, Chapters 3-5, looks closely at historical and current theoretical literature on political representation, applying foundational understandings of these concepts to the new demands for citizen representatives in global settings. Emerging political theory that attempts to address the problem of non-elected citizen representatives in the global sphere is discussed. This section of the project takes seriously Mansbridge's (1983) claim that the kind of representation needed depends on what the representation is for, exploring the potential gains and losses when inclusive representation is utilized and identifying when representatives who come from, or are selected by, marginalized groups are most required. Further, this section examines both the anticipated benefits and the potential obstacles to creating processes for decision making that are liberatory for marginalized people. The third part of the project, Chapter 6, explores two different social movements that have led to formal inclusion in global decision-making processes: the Indigenous Rights movement and the creation of the United Nations Permanent Forum on Indigenous Issues; and the movement by people living with HIV and the establishment of the NGO Delegation to the Programme Coordinating Board (PCB) of the United Nations Joint Programme on HIV/AIDS (UNAIDS). Examining the trajectories taken by each group, this section of the project looks

at the similarities and differences in group organizing and the forms of power each group has within the processes for inclusion that have been established. In the final section, Chapter 7, criteria are proposed for creating, and evaluating, inclusive representation processes in global institutions. In addition, a set of three tensions that any process of representation must address is described. The criteria and the tensions, together, form a framework for working through key issues related to political representation in global bodies. The end of the chapter focuses on evaluating the Permanent Forum and the UNAIDS Programme Coordinating Board based on this framework. The project concludes with a summary and a call for further work to better understand how power flows within representation processes in global institutions.

**CHAPTER 2 INCLUSIVE REPRESENTATION: DEMOCRATIC CRITICISMS AND RESPONSES**

“For over two decades, the Indigenous people of the Americas have carried their struggles and debates to the United Nations arena, demanding a process of democratization of the international body...”

Director of the Indigenous Research Center of the Americas at the University of California,

Davis, Stefano Varese 2006, 231

The problem that this project seeks to address stems from the systematic marginalization of some groups of people within their own countries. This marginalization makes members of these groups vulnerable to a host of human rights violations and leaves them with little recourse within the state for protection from, or remedies, to rights violations. In response, global institutions have increasingly crafted governance processes designed to increase the meaningful participation of these groups. These processes are recent developments, with the earliest dating from the 1982 establishment of the United Nations Working Group on Indigenous Issues. In the main, these processes have been created in isolation from each other and in reaction to social advocacy campaigns. Those designing inclusive processes have done so without the luxury of systematic attention to the assumptions underlying the processes crafted or the benefit of the rich literature from political theory and the social sciences drawn from generations of theory and practice of political representation.<sup>2</sup>

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<sup>2</sup> One possible exception to this general description could be the Global Fund to Fight AIDS, Tuberculosis, and Malaria and the processes designed for representation at the global and country level. The Global Fund adopted an iterative learning process; from this, weaknesses have been identified in the processes for inclusion of members of civil society and addressed through structural changes that require inclusion as a condition for state-level funding.

This chapter explores the concept of inclusive representation through addressing a series of criticisms about the movement for increased involvement of marginalized peoples in supra-state processes. The overarching question of this chapter is whether inclusive representation is a goal that ought to be pursued: specifically, is it a goal that meets democratic criteria and is it a goal that is possible to accomplish? This chapter argues that inclusive representation is both – it enhances democracy and can be designed to be effective and meaningful – and sets forward some possible parameters for a pragmatic practice of inclusive representation.

Critiques of the concept of increased inclusion for marginalized peoples have been rare, presumably because most of those engaged in this question became involved out of a commitment to bringing people who would be otherwise left out into decision-making about matters that affect them. The arguments in favor of the inclusion of marginalized peoples center on two factors: a) inclusion is the right thing to do because it is democratic; and b) inclusion makes decisions and programs more effective. By contrast, most criticisms have focused on the ways in which these processes have been implemented. Instead of opposing the project for greater inclusion, these criticisms spring from support for the project, focusing on ways in which processes have been inadequately inclusive.

However, there are some situations in which tensions have erupted. In some cases, state representatives to global bodies have objected to the inclusion in decision-making processes of civil society organizations when those organizations promoted human rights policies that conflicted with state practices. In other cases, the conflicts have been between different communities, such as when majorities are barred from initiating policies they want because of particular minority protections.

For example, conflicts between UN member State representatives and civil society representatives have developed over powers given to civil society representatives to participate in global forums. During the 2011 and 2012 meetings of the UNAIDS Programme Coordinating Board (PCB) which is the governing board for UNAIDS, the representatives from Egypt, Iran, and an African bloc of states (who later dropped their resistance) vocally opposed a series of recommendations put forward by the NGO Delegation to the board in their 2011 annual report (Coulterman 2011a, 2011b, 2012). The recommendations called for states to “oppose and repeal laws that criminalize HIV non-disclosure, exposure or transmission, homosexuality, gender identity and/or expression, abortion, sex work and drug use”(Simon 2011). At the June 2012 meeting, some member states requested that the NGO Delegation not be allowed to include “decision points,” or recommendations, in their future reports to the board (Coulterman 2012). The effect of this change, which was subsequently accepted, will be to limit the power of the NGO Delegation to frame the agenda in future PCB meetings (UNAIDS PCB Bureau 2012).

In other situations, tensions have arisen when processes designed to respect the wishes of marginalized groups provided outcomes that conflicted with what was seen as the national interest or the wishes of governments. For example, Peru was among the initial 144 signatories to the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) in 2007, committing to obtaining the Free, Prior and Informed Consent (FPIC) of affected Indigenous peoples before engaging in activities that substantially affect them. Yet in a 2012 development project, the Pakitzapango hydroelectric dam, the Peruvian government did the opposite. They neglected to inform the local Indigenous community, the Ashaninka, of the plans for the dam even while awarding land concessions

and conducting feasibility studies. The dam is anticipated to generate power that can be exported to Brazil in exchange for funds that can be used for national development, supporting President Humala's social agenda for improvements for Indigenous and impoverished Peruvians. However, if the project is implemented, the majority of the Ene river basin, where the Ashaninka live, will be flooded (Nelson 2012). The controversy over Peru's dam project is one of many examples worldwide where government wishes to meet national development needs in certain ways are pitted against the rights of Indigenous minorities to protect their land, ways of life, and livelihoods (see, for example, Lyons 2012 on the Belo Monte dam in Brazil and Khagram 2004 for the history and politics of the Narmada Projects in India).

### ***Democratic critiques of inclusive representation processes***

As described in the Introduction, supporters of increased inclusion have given limited energy to theorizing inclusive representation to date; similarly, opponents have yet to sketch out a full critique. Despite this, a sympathetic reading of the concerns expressed by state actors, or that might be put forward by majority populations, allows identification of three potentially serious criticisms:

1. Is it anti-democratic to elevate the *voices* of particular groups in global and national decision-making?
2. Is it anti-democratic to increase the *influence* of particular groups in global and national decision-making?
3. Is it possible in practice to determine fairly which groups should be eligible for processes to increase voice and influence and which should be excluded?



This chapter addresses each critique in order: first, examining the extent to which the rights of majorities might be violated by amplifying the voice of marginalized groups or, assuming amplification can be acceptable in democratic terms, the extent to which majority rights might be harmed by increasing the influence of marginalized groups on outcomes. This chapter presents the that increased voice and increased influence for marginalized groups do not violate the rights of majorities, and, further, enhance the democratic legitimacy of decision-making processes. Next, this chapter addresses concerns about the impossibility of identifying the appropriate groups for inclusion. Serious challenges to processes of inclusive representation are raised by this critique. In response, proposed criteria for determining the characteristics of groups who are required to be at the table for a process to be considered inclusive are offered.

### ***Conceptions of democracy at a global level***

The first two of the three criticisms center on possible violations of democratic principles. Before examining the criticisms individually, this section provides an orientation to different approaches to thinking about what democracy at a global level might mean.

Many definitions of democracy focus on identifying minimal criteria, usually based on electoral processes, for determining whether or not a state should be considered a democracy (see, for example, Dahl 1989, Huntington 1991). However, global governance functions primarily without elections. To explore questions about democracy in global institutions and organizations requires a deeper look, beneath the process of elections, and an examination of why it is that democracy *matters* in global affairs?

Three different statements can be identified as ways that democracy is conceptualized at the global level. Each statement highlights a different democratic ideal:

**Table 1: Conceptions of Global Democracy**

State-centric	Each state—and through the state, its citizens—has formally equal status in global decisions. States are responsible for bringing their population’s concerns to global bodies, whether or not those concerns are democratically determined.
Global public sphere	A global public sphere is created where groups of people can seek to be heard when other democratic processes have failed to provide them with a meaningful voice in particular decisions that affect their life chances.
Equal respect and concern	Global decisions provide equal respect and concern to all persons, no matter in which country or region they live.

**Democracy belongs to states, not to global institutions.**

The first statement defines democracy as something that does not exist at the global level, beyond the choices made by states to represent the wishes of their populations. Instead, states have the right to participate in global governance on a formally equal basis with one another. The result of this sovereign equality among states is that citizens in small, low-resource, or less powerful countries have a formally equal voice – although, nowhere near equal influence – with those in large, wealthy, or more powerful countries.

### **Access to a global public sphere**

The second statement presents a vision of a democratic global public sphere where people from around the world can present their concerns, interact with others who may have similar, complementary, or opposing concerns, and attempt to organize support. The global public sphere may be physical, such as when civil society groups come together around UN meetings or for protests of the G8 or World Trade Organization meetings. It can also be virtual, for example, such as when dialogue space is developed through social media or on-line discussion platforms. The idea of the democratic global public sphere takes inspiration from Habermas's (1996) insistence that vibrant public spheres and processes of deliberation are essential for political equality (see also Dryzek 2007). For Habermas, the public sphere is a space where anyone, however situated in her own society, can bring forward concerns and proposals for public attention. If her concerns or proposals are to be considered, they must be backed by reasoned arguments that others can accept. The extent to which a person can find support is dependent only on the strength of her arguments, not her social status. Extending this concept to the global level, the function of the democratic global public sphere can be understood as providing attention, and possibly other kinds of recourse, to people who are excluded from the respect and concern by their state. The goal for these communication and organizing efforts is to use global attention to affect state policies.

A challenge for this view of global democracy is that it presupposes that groups marginalized within their own countries can find a way to bring their concerns to an international audience. However, this is not as impossible as would seem at first glance. The opportunities for representation within international organizations gained by

Indigenous peoples and people affected by the HIV/AIDS epidemic provide examples of how marginalized groups can gain this attention at global levels (for additional examples, see Keck and Sikkink (1998) on transnational advocacy networks).

### **Access to equal respect and concern in global decisions**

The third statement reaches farther, offering a vision of democracy in which people from anywhere in the world, when their own states fail them, can have meaningful access to the attention and concern of global decision-makers. This idea builds on, then extends, Dworkin's (1999) argument that the meaning of democracy is to provide "equal respect and concern" to all members of a political community. For Dworkin, democracy is realized only when all members of the political community are "moral members" in that community. A political community must meet three relational conditions to determine moral membership.<sup>3</sup> Dworkin writes, "[a] political community cannot count anyone as a moral member unless it gives that person a *part* in any collective decision, a *stake* in it, and *independence* from it" (103). Contained within the three relational conditions is the idea of influence. Dworkin explains:

Each person must have an opportunity to make a difference in the collective decisions, and the force of his or her role—the magnitude of the difference he or she can make—must not be structurally fixed or limited in ways that reflect assumptions about his or her worth or talent or ability, or the soundness of his or her convictions or tastes (103).

But what if the political community does not do these three things for all of its members? If it does not, then the basic democratic conditions are violated. When collective decisions are made, only those who are moral members in the political community are

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<sup>3</sup> In addition to relational conditions, Dworkin (1999) specifies structural conditions that are required for a genuine political community. The structural conditions include such factors as shared geography, identity, and history, among others (103). These factors

engaged in self-government. If there are others, even if those others have an equal vote, they are excluded from self-government. In that case, the democracy requires new procedures that do provide equal respect and concern. In this vision of democracy, the focus of citizen engagement is on global actions to set standards or press states to be more inclusive rather than seeking to influence states to pass supportive policies or remedy injustices. However, there may also be additional focused efforts at the state-level to press states to adopt these global decisions.

This conceptualization of global democracy includes, and goes beyond, the ideal of the public sphere. The global public sphere is process oriented, requiring no particular outcomes of equality so long as conditions exist to allow open dialogue. By contrast, the emphasis on equal respect and concern requires a fair chance for people to have their needs heard and equally considered by decision makers and it requires that the outcomes of decision-making processes distribute costs and benefits in ways that are generally equitable by some clear criteria. This is to say, while there may be uneven distributions for any given decision, no groups should find themselves consistently excluded from political influence while others set the policies for and reap the benefits of their shared political life.

The fundamental tension for global decision-making processes is the attempt to balance the different values that each of these democratic visions promotes.

### ***Responses to the critiques***

The next sections discuss the three critiques of inclusive representation in turn.

**Does increasing the *voice* of marginalized groups in decision-making violate democratic principles?**

Inclusive representation creates spaces beyond the level of the state in which members of particular marginalized groups can give voice to their interests, perspectives, and needs. However, as all individuals do not share equally in this access to speak in the halls of global decision making, such processes can raise concerns that global processes are rigged for certain outcomes, designed to give disproportionate attention to the needs of some small groups of people, and are, therefore, essentially undemocratic.

The opening chapter provided examples of current processes to increase the voice of members of marginalized groups in decision-making processes that serve to illustrate the kinds of situations to which this critique refers. In these examples, formal, on-going positions have been established to allow input into decisions by groups of people who are marginalized within most states: Indigenous Peoples and those living with and affected by HIV infection. These two groups differ from each other in many respects, described in the case studies in Chapter 6. One similarity is important for understanding the representative processes described in this section: these representatives have been invited to speak within a global institution (the United Nations) by virtue of the marginalized status of their groups. With access to speak but not to vote and with no rules for determining a standard of fairness for outcomes, this situation corresponds to the global public sphere concept of democracy described in the previous section.

Consistent with the first vision of global democracy described previously, international institutions, such as the United Nations and the organizations within the UN system, were founded upon the principle that state leaders, or their appointed representatives, speak for each state. Citizens of the state were to address their concerns to

their leaders within the state. Representatives from democratic countries may be perceived as having more credibility when they speak for their citizenry; however, democracies and non-democracies alike are viewed as the legitimate voices for the interests of their states.<sup>4</sup> Representatives of marginalized groups all live within and come from states; they are individual citizens within states. According to traditional understandings of international institutions, individual citizens do not represent themselves or any group of which they are a part at the global level; rather they are represented by those who are appointed to speak for their state as a whole.

This system breaks down in an important way that speaks to the question of inclusive representation: some groups are persistently excluded from any kind of meaningful attention within their state because of their low social status. These groups are subject to the “relations of the ban” which excludes them from participation alongside others as equal participants in self-government (Agamben 1998). Biases by dominant groups, whether based on race or ethnicity, religion, language, gender, sexual orientation, disability, or other stigmatized status, ensure that these marginalized groups have, at best, limited power to get their issues on the political agenda, to get a fair hearing, to build coalitions with others in the state, or to enact beneficial policies for their group, while members of dominant groups wield all of these forms of power within the state on their own behalf.

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<sup>4</sup> Certainly quite visible democratic deficits exist at the levels of global governance. The UN Security Council is the prime example of this, as are the power imbalances between high-resource and low-resource countries that limit meaningful equality of voice in such powerful bodies as the World Trade Organization, the World Bank, and the International Monetary Fund. However, the existence of other democratic deficits does not remove the concern to see inclusive processes at this level for marginalized groups.

Descriptions of catalysts for Indigenous rights movements frequently focus on the lack of access to state governments as a primary cause for transnational organizing and global advocacy work. For example, speaking of the 1970s Canadian First Nations movements, Dahl (2009) writes, “Even in a democratic country such as Canada, all appeals for respect for the unique Indigenous cultures were in vain. Faced with this situation, the Indigenous peoples looked outside their communities and countries for support” (35). Similarly, Chirif (2006) describes Indigenous societies in Latin America as having “deep democratic roots and yet [are] not subject to the representational processes on which our society claims to base the principles of democracy” (15). Reporting on a series of interviews with Indigenous rights activists in Latin America, Brysk writes, “With some exceptions, Indian-Latin political partnerships have been hindered by geography and cultural isolation, the class-based character of opposition forces, *and lack of interest in resource-poor Indians by other sectors of civil society*. A spectrum of Indian leaders from Brazil to Honduras stated that they sought international help because ‘we had no real support at home’” (Brysk 2000, 63, emphasis mine). In some cases, even these groups’ identities as peoples that exist across state boundaries, with shared concerns and common interests, have been crafted because of their marginalized status within their own particular states. Brysk quotes Ecuadoran leader, Blanca Chancosa, “Indian identity is imposed—we have our own names. But if they call us Indians, we will rebel as Indians” (2000, 57).

A second issue requires attention: chief among the requirements frequently posited for a democratic system (Dahl 1989) is access, particularly on the part of decision makers, to information that broadly reflects the experiences and interests of their constituents.



When some members of any political community are persistently excluded in decisions about the issues that affect their lives, the result is that the information that they can bring to decision-making processes from their lived experiences is lost. If this information is lost at the state level, it cannot be represented in global fora by government leaders appointed to speak for their states. When states enact policies at home and when their representatives speak in global fora, the needs of members of these groups are excluded from consideration. This situation is the essence of non-democracy as certain classes of people, because of their low status, are ruled by the decisions of others with no voice in decisions that affect them. No plausible definition of democracy calls for the consistent silencing of minorities in favor of discriminatory majorities.

This exclusion from consideration by states within global venues is illustrated by the arguments made by the representatives of Egypt and Iran during the 2011 and 2012 UNAIDS PCB meetings that certain key populations related to the HIV epidemic do not exist in their countries and legal protections would be inappropriate in their country contexts (Coulterman 2011b, 2012). In a strikingly similar parallel, Soguk (2007) describes strategies used by states to avoid political recognition of Indigenous peoples upon the signing of the UN Declaration on the Rights of Indigenous People (UNDRIP). Soguk describes public statements by China and India voicing support for Indigenous peoples, followed by denials that any exist within their countries (18). In the UNAIDS situation, the presence in the room of the NGO delegates lead to a direct challenge to Egypt and Iran's claims, with civil society delegates and observers standing together in support while Joël Nana, an openly gay delegate from Cameroon, made a passionate plea in gentle tones for the board to recognize that while:

[T]here are many parts in Africa, where I come from, where people have not even started implementing MSM [gay, bisexual, and other men who have sex with men] programs or programs for sex workers; it doesn't mean that they do not exist in those countries. They do exist in all those countries. We do exist in all those countries (Nana 2012).

Focusing on the U.S. political system, where democratic concerns are periodically raised about role of the Supreme Court, as a powerful but unelected branch of government, Ely (1980) argues, nonetheless, that Supreme Court interventions to assure equal treatment are essentially democratic in nature. Ely views majority rule as the legitimate democratic practice except in very specific cases. When situations occur in which some groups are so disliked that they are unable to use normal political processes, such as creating alliances with other groups to press for attention to their needs, then, Ely argues, additional processes are needed to ensure that members of these groups can enjoy full participation in political life. Ely writes, "The whole point of the approach is to identify those groups in society to whose needs and wishes elected officials have no apparent interest in attending" (151), a required element for this identification is that "the minority in question be one that is barred from the pluralist's bazaar...for reasons that in some sense are discreditable," unable to form coalitions or to have their interests even considered by members of dominant groups because of biases and discrimination (152-153). Viewed with these undemocratic country-level practices in mind, the inclusion of voices of marginalized peoples in global decision-making becomes a democratic remedy. Without this remedy, global politics inevitably reinforce anti-democratic country practices.

**Does enhancing the *influence* of marginalized groups in decision-making violate democratic principles?**

A focus on the influence of marginalized groups in decision-making highlights the extent to which members of these groups can directly and effectively shape outcomes. This

question incorporates the idea of increased consultation with marginalized people and goes beyond this to the question of the justice, in democratic terms, of providing direct influence. Strategies to increase the influence of marginalized groups range from providing reserved seats, with equal voting powers, on decision-making bodies (such as those for developed and developing country NGOs on the global board of the Global Fund to Fight AID, Tuberculosis, and Malaria) to veto power over certain state or global decisions (for example, for Indigenous Peoples regarding certain kinds of development projects under World Bank Policy OP 4.10 (2005)). An important caveat is needed here: Indigenous Peoples' rights over land and development are founded in the idea of a prior right and in principles of self-determination of disparate political communities rather than general democratic concerns. This current project seeks to determine whether processes to increase the influence of Indigenous Peoples, as well as other marginalized groups, can *also* be supported under democratic principles.

The Global Fund to Fight AIDS, Tuberculosis, and Malaria (Global Fund) is a private-public partnership established in 2002 by private donors, international institutions, and states to coordinate global funding to address the triple epidemics of AIDS, tuberculosis, and malaria in low-, and some middle-, income countries. An example from the Global Fund illustrates the concern about increased influence: The funding processes developed by the Global Fund require countries to establish bodies, called Country Coordinating Mechanisms (CCMs), with participation from public officials, private or business partners, and civil society organizations, to set national HIV/AIDS strategies, develop funding priorities, apply for project funding, and, if successful in their application, monitor implementation of projects. Initially, the Global Fund set guidelines, rather than requirements, for

participation; however, these were often ignored. In response, mandates have been increasingly specified. Currently, CCMs are required to demonstrate that their members include people living with HIV -- and people affected by tuberculosis or malaria, if funding is requested for these diseases -- before they are eligible to be considered for funding. Communities of people living with the diseases have the right and responsibility to select their representatives. The representatives from civil society, including people living with HIV and affected communities, hold equal voting rights on the CCM. In addition, CCMs must demonstrate that they have consulted with key population groups, which the Global Fund defines as “women and girls, men who have sex with men, transgender persons, people who inject drugs, male and female and transgender sex workers and their clients, prisoners, refugees and migrants, people living with HIV, adolescents and young people, vulnerable children and orphans, and populations of humanitarian concern” (Global Fund 2011, 8).

The previous section discussed ways in which ensuring an enhanced voice for marginalized people can be supported using democratic principles, focusing on the increase in the relevant information, perspectives, and needs that are brought into the public sphere for consideration. However, providing increased influence in the outcomes of decisions raises additional concerns. Three issues are of particular relevance:

- 1) For decisions that are taken in state-centric, multilateral institutions, such as the United Nations, amplifying the influence of some groups in society seems to circumvent existing processes by which states determine how to press for state interests within global fora.

- 2) Increasing the influence of members of marginalized groups has the de facto effect of minimizing the influence, and thus, attention to the needs of members of majority groups.
- 3) The increased influence for marginalized groups can come at the expense of those, such as the poor, who are subordinated members of majority groups.

These issues are most challenging for democracies, as their processes are legitimated by elections in which the citizens select their nation's leaders, who then make national policies and appoint international representatives. However, it is also challenging for non-democracies as their leaders are recognized at global levels as the legitimate decision-makers for the polity. If democratic principles are to be defended under principles of equal respect and concern for all members of a political community, then these issues require consideration. Are members of majority groups, or of other oppressed groups, harmed when specific decision-making rights are conferred on marginalized groups who are excluded through normal political processes?

In terms of any possible harm to dominant majority groups within countries, the rationale for increasing the voice of marginalized groups, described in the previous section, holds just as strongly as a rationale for increasing their influence. The interests of dominant groups are already strongly represented within decision-making processes, whether state or global. Even with the current global structures of inclusion for Indigenous Peoples and people living with HIV, in the end, at the global level, dominant groups have the final word.

Certainly, the power of either Indigenous Peoples or people living with and affected by HIV should not be overstated. Neither is able to override state policy preferences in substantial ways. State commitments under UNDRIP are honored more often in their

breach. In a recommendation for a special session focused on good governance, the 2014 Report to the Economic and Social Council on the 13<sup>th</sup> Session of the UN Permanent Forum on Indigenous Issues (E/C.19/2014/11) summarizes violations faced by Indigenous Peoples seeking to influence policies that affect them:

Many examples of bad governance were cited, in particular with regard to bureaucracy, such as Governments making decisions without indigenous participation, consultation, or free, prior and informed consent; Governments making policy in centralized locations without input from indigenous peoples; and the imposition of new policies and programmes without any notice. Such actions lead to disempowerment, a lack of identity and violations of indigenous peoples' human rights. In particular, some States have policies that criminalize indigenous peoples when they exercise the right to self-determination, including over their lands and territories.

Similarly, one measure of influence for people living with HIV would be greater access to medical treatment. Access to medications shows up as the top priority for people living with HIV worldwide (People Living with HIV Advocacy Agenda 2012, NGO Delegation 2014b). Yet, in 2013, only 38% of adults with HIV in low- and middle-income countries who needed treatment were able to access the medications that they need to stay alive. For children with HIV, the number drops to 24% (UNAIDS 2014a).

These realities highlight the critical issue at hand, which is that these are such deeply marginalized groups that even global treaties and international institutions set up to attend to their needs cannot assure the outcomes for which they were designed. Further, the democratic deficits that these groups face may not even be remedied by solutions to increase the influence of marginalized peoples. In his opening remarks to the Regional Meeting of Indigenous Peoples on the World Conference against Racism, Racial

Discrimination, Xenophobia and Related Intolerance, Dr. William Jonas<sup>5</sup> described the limited influence that participating in consultations has on outcomes:

It is important to note...that the World Conference is ultimately a meeting of UN member states. While participation and contributions from...affected groups such as Indigenous Peoples [are] being actively sought, at the end of the day it will be the governments of the world who will negotiate and commit to a program of action at the World Conference (2001, 38).

However, for other subordinated groups, such as women or the poor, the concern about increased influence for some marginalized groups is more substantial. Countries struggle to raise funds to develop social, educational, employment and health systems for their citizens (United Nations 2012) and may view natural resources in areas traditionally belonging to Indigenous Peoples as the solution for relieving some of the struggles of the poor. In health fields, concerns have been raised about whether the focus on HIV funding has hurt the response to other health conditions (see, for example, Bongaarts and Sindig 2009, Schiffman 2008). While the studies to date have demonstrated positive effects on the ability of health systems to address other health issues, resulting from HIV funding (Shepherd et al. 2012, Yu et al. 2008), the resonance that this concern continues to have demonstrates the fear that the health needs of others in the population will be overlooked.

Responding to concerns about the effects of increased influence for some marginalized groups is critical. Without ensuring protection of the interests of the diversity of those subordinated within the county, dominant groups can simply play different oppressed groups off each other. Dominant groups would, as a result, continue to enjoy undue access to resources and the benefits that accrue from the state.

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<sup>5</sup> Aboriginal and Torres Strait Islander Social Justice Commissioner, Australian Human Rights and Equal Opportunity Commission.

To return to the Global Fund example, the Global Fund requires countries to allow people living with and affected by HIV substantial influence in determining what grant proposals are submitted. Countries do have a choice about whether they seek Global Fund grants; however, for countries with high epidemic burdens that are straining to meet even basic health care needs, the freedom to choose whether or not to ask for funds is severely compromised. Because the Global Fund requires countries that seek funding to establish CCMs with strong civil society representation and voting power and because the amount of funding is significant for most countries, if funding is granted by the Global Fund, decisions by the CCMs can effectively set domestic health policies and programs. These policies and programs may conflict with the choices that majorities, and their representatives in government, support. While these majorities have the power within government and society to ensure that their needs are also met, what happens to other subordinated groups with serious health concerns who lack the clout needed to assure attention to their wellbeing?

Further illustrating this concern, from the perspective of Indigenous rights, Marcus Colchester, anthropologist and former director of the Forest Peoples Programme, writes:

Many of the objections to both Indigenous rights in general and the right to Free, Prior and Informed Consent in particular have come from assertions that recognition of this right poses an obstacle to national development. If Indigenous peoples are 'granted' the right to veto proposed developments that will affect them or affect their lands, territories and resource, it is claimed, then valuable opportunities for countries to emerge from poverty will be blocked (2010, 11).

Again, it is likely that one oppressed group – specifically, the poor – will bear the costs from the increased influence that another oppressed group – specifically, the Indigenous – gains. However, to assume that only one marginalized group can be included at a time is to accept



a false dichotomy. In the next section, I present criteria for determining which groups should be included in particular decision-making processes. These criteria support inclusion of multiple subordinated groups, depending on the issue under consideration. While this inclusion does not guarantee any particular marginalized group the ability to control the decision-making process – a control they would not have even if they were the only marginalized group represented – it does guarantee that different marginalized groups are able to work directly with one another on decisions without having their concerns filtered through dominant groups. This limits the opportunities for dominant groups to insist that issues are zero sum with one subordinate group or the other guaranteed to be the loser while dominant groups present themselves simply as referees.

Having the ability to weigh in through a vote or a process that seeks consent provides some ability to ensure that your needs, as a member of a marginalized group, are actually counted within the decision-making process. Within democratic processes, the members of marginalized groups may still lose, but there is, at least, a record left of their support for their position and a chance to persuade others to join the cause. Further, if you are at the table as a representative of marginalized populations, then, at a minimum, representatives of states must cast their votes to your face rather than behind your backs.<sup>6</sup>

To return to the question of why inclusion matters in these cases, the clearest argument can be found in Dworkin's claim that the essential democratic condition is "equal status for all" (Dworkin 1999). An examination is required of the challenges to achieving "equal status for all" within inclusive processes for dominant and marginalized groups. For marginalized groups, inclusive processes do not guarantee equal status but they do create

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<sup>6</sup> Thanks to Gorik Ooms for this point reflecting his experience serving on the Mozambique CCM, personal conversation, Johannesburg, March 23, 2011.

the possibility, otherwise missing, for this democratic condition to exist. As Young (1989) contends, “a major reason for explicit representation of oppressed groups in discussion and decision making is to undermine oppression” (262). Dominant and majority groups generally exist in a condition in which they are “more equal than others,” able to shape policies as they wish, whether or not they themselves are particularly affected by the outcomes. Dworkin writes, “When majoritarian institutions provide and respect the democratic conditions, then the verdicts of these institutions should be accepted by everyone for that reason. But when they do not, or when their provision or respect is defective, there can be no objection, in the name of democracy, to other procedures that protect and respect them better” (1999, 96). The legitimacy of adopting such “other procedures” relies on a determination of whether the state’s “provision or respect is defective”. How to determine this is the focus of the next section.

To conclude the discussion of the democratic legitimacy of processes to enhance the influence of marginalized groups, two aspects need to be highlighted: First, these processes only exist for specific marginalized groups in bounded topic areas that affect the life chances of group members in a significant and unique way. That is, inclusive processes are not created to give enhanced decision-making power to marginalized groups on issues that affect everyone within the population equally. Second, the processes are designed because the groups are marginalized. Should conditions change and the marginalized group experience treatment as equal members of the political community, as demonstrated by such conditions as the ability to have their issues highlighted within political coalitions, put issues on the agenda, see their issues receive serious consideration, and win broad support

for electoral offices, then the inclusive processes that were set up to assist in gaining equal status would no longer be necessary for that group.

The exclusion of equal respect and concern for the groups under consideration for this project – Indigenous Peoples and people living with HIV – as well as racial, ethnic, and language minorities; immigrants; and even women; is long-standing and deeply ingrained. While maintaining the possibility for democratic change, such change is not imminent. As a result, this project only roughly sketches the criteria for determining when a group would no longer be eligible for specific inclusive processes. Instead, this project adopts Laclau and Mouffe's (2001) compelling argument that political equality for subordinated groups is an on-going struggle – a “war of position” in Gramscian terms – such that advances toward equality for one group allows attention to move to additional groups that face domination. As such, inclusive representation processes will have the greatest democratic potential when they are structured for the inclusion of new groups as these groups are identified.

**Is it possible to establish fair criteria for determining which groups, or characteristics, should be eligible for processes to increase voice or influence?**

The concern addressed in this section is a criticism on pragmatic grounds. Assuming that inclusive processes can be supported in democratic terms, this concern asks whether it is possible to determine which groups ought to be included. The essence of the problem is that, for any issue, many stakeholders can be identified who would have some claim to participate if the criterion is solely that they expect the outcomes will affect them. In addition, with multiple issues involved, the groups of affected people can shift depending on the issue and new affected groups can emerge, potentially bringing even more people to the table. The easy response is to ignore the practical difficulties and include everybody who claims to have a stake. However, this is not possible in practice. The inclusion of too

many representatives creates bodies too large and unwieldy to act. As a result, everyone's voice is diluted, dominant groups have the advantage, and the democratic potential for bringing marginalized people to decision-making bodies is lost.

The complexity involved in crafting inclusive processes is demonstrated by an example:

The proposed TransCanada Keystone Pipeline would move tar sand oil from the Canadian province of Alberta south through the United States to the Gulf of Mexico. Indigenous Peoples in both countries oppose the project, which is expected to affect Indigenous communities through pollution, excavation, disruption of archeological and sacred sites, and risks of oil and chemical spills. Pipeline proponents, largely legislators who are members of the Conservative (Canada) and Republican (U.S.) parties, argue that this project will help reduce U.S. dependence on Middle Eastern oil, create jobs in both countries, and provided significant revenues for both countries (Dembicki 2011, Broder 2012). Opponents cite environmental degradation of the boreal forests, river waters, and water table; increased human health dangers, pointing to the emergence of new cancers in First Nations communities downriver from the refineries; and violations of the rights of Indigenous peoples through failures of the governments in both countries to seek their consent for the changes that will affect their lands and their well-being (Dembicki 2011, Worth 2012). Permission to work on the southern portion of the pipeline, from the State of Oklahoma to the Gulf of Mexico, was granted by the U.S. government in June 2012. After an initial rejection, TransCanada resubmitted documents requesting permission to start work on the northern section in May 2012 (Broder 2012). As of January 2015, TransCanada had

filed eminent domain papers in Nebraska courts in an attempt to seize the final lands needed for the northern section (Wilson 2015).

If an inclusive process were to be developed for the Keystone Pipeline project to amplify the voice and the influence of marginalized groups, who are the stakeholders who would need to be involved? First, following the provisions agreed to in the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP), any inclusive process would need to include all affected Indigenous peoples through their representative institutions. When member states of the United Nations adopted the UNDRIP, they signaled their commitment to “consult and cooperate in good faith with the Indigenous peoples concerned through their own representative institutions in order to obtain their free, prior and informed consent before adopting and implementing legislative or administrative measures that may affect them” (Article 19) or “prior to the approval of any project affecting their lands or territories and other resources...”(Article 32). Canada and the United States endorsed the UNDRIP in 2010. However, obtaining the free, prior and informed consent of the Indigenous peoples concerned is more complex than the phrase implies. In the case of the Keystone Pipeline, the kinds of issues requiring attention can be suggested as:

(1) whether Indigenous peoples on each side of the U.S./Canada border should be consulted together or separately;

(2) what representative institutions are in place to represent Indigenous peoples and whether each Indigenous nation and local community has separate institutions;

(3) the extent to which the institutions represent the people in transparent and accountable ways and are, thus, authorized to join agreements that affect the land and the ways of life of the people; and

(4) whether specific outreach is required to ensure that Indigenous women, the elderly, and the young are all included in the decision-making process.

A working paper for the World Bank summarizes experiences from processes designed to respect Indigenous peoples' rights to informed consent:

Even working through local leaders may not be sufficient. Informed consent should be seen first and foremost as a process that embraces all stakeholders. It is not an issue that should be delegated to representatives. An Indigenous leader rarely is empowered to speak for everyone. At the very least there are several key groups that should be consulted, e.g. elders, women and young men (Clay et al. 2000, 11).

In addition, a process designed to meet the democratic criteria of giving voice and influence to marginalized people about the decisions that affect them, as outlined earlier in this chapter, requires one to think more broadly than simply ensuring that UNDRIP is not violated. Local groups with a stake in the outcome include non-Indigenous people living in areas affected by the pipeline, including, among others, residents, immigrants and migrant workers, and local farmers and ranchers, particularly those who are reliant on the water that is diverted to support the project or polluted by residue or leaks in the pipeline. Other stakeholders include oil companies, workers, environmentalists and nature tourists, local and national politicians, and, potentially, people throughout the U.S. who see their oil prices decline or who may benefit from reduced U.S. reliance on oil from the Middle East. How can an inclusive process be established to allow effective input from stakeholders when, at some level, almost everyone can stake a claim?

Developing these criteria requires that attention be returned to the purpose for inclusive representation: to ensure meaningful participation for people who would otherwise find themselves dominated within their polity. Political theorists, working from this foundation, have proposed specific criteria for when inclusive representation is appropriate. To this end, Held (2003) describes three democratic benefits that result from increased participation for marginalized groups: inclusiveness for those most affected by decisions; subsidiarity, through bringing decision-making processes to the level of those affected by decisions; and equivalence of voice in decisions, through better leveling of the power differences between marginalized and dominant groups of people. From these, he proposes basic criteria for determining who should be involved:<sup>7</sup>

The principle of inclusiveness and subsidiarity is often regarded in democratic theory as a helpful means to clarify the fundamental criterion for drawing proper boundaries around those who should be involved in particular decision-making domains, those who should be accountable to a particular group of people, and why. At its simplest, it states that those significantly (i.e., nontrivially) affected by public decisions, issues, or processes should, *ceteris paribus*, have an equal opportunity, directly or indirectly through elected delegates or representatives, to influence and shape them. Those affected by public decisions ought to have a say in their making (10).

Held specifies that “significantly affected” refers to “those whose life expectancy and life chances are significantly affected by social forces and processes” (12).

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<sup>7</sup> Held also develops criteria for determining when supra-state decision-making processes are legitimate. For Held, this happens in situations within which people’s life chances are shaped by processes that occur outside of their state and cannot be addressed adequately by state-level governance, such as environmental, economic, and health issues with effects that cross borders. He claims that, in these situations, “the principles of inclusiveness, subsidiarity, and equivalence can only be properly upheld in a transnational context” (17). Note that these issues comprise many of the most significant areas that affect human wellbeing.

In related work, Young (1989) and Mansbridge (1999) seek to identify when a particular form of inclusive representation, descriptive representation, is warranted.<sup>8</sup> Young writes, “[r]epresentation should be designated whenever the group's history and social situation provide a particular perspective on the issues, when the interests of its members are specifically affected, and when its perceptions and interests are not likely to receive expression without that representation” (265-266). Mansbridge (1999) further develops the criteria, arguing that there are three specific conditions that call for representation of marginalized groups: first, when members of marginalized groups lack trust in official decision-making bodies; second, when they need to challenge negative public perceptions about group members’ ability to contribute meaningfully to political life; and third, when the decision-making body is likely to consider new issues for which group positions have not yet developed.

Under each of Mansbridge’s conditions, a representative who comes from outside the group, even if selected by group members, will lack the ability to shift the situation of the group from a state of dominance to one of equality. In the first case, alienation from the governing systems will not be overcome by a representative who is not from the group, primarily because group members will not have the assurance that their representative will be affected by decisions in the same way that they are. In the second case, electing a non-group member to represent the group cannot overcome the stigma faced by group members and could, instead, reinforce the stigma by continuing to make it appear normal and acceptable to have a governance body within which certain groups are perpetually excluded. Finally, any representative will struggle to address new and unanticipated issues

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<sup>8</sup> Different types of representation as described by Pitkin (1967) are explained in detail, with particularly attention to descriptive representation, in Chapter 3.



that emerge and call out for resolution. However, as Mansbridge explains, a representative from the group, who shares the group's history and experience, has a better chance of responding in ways that support the group's needs.

Taken together, these statements provide a set of criteria for designing processes for inclusive representation in decision-making processes. Six questions can be asked, based on the work by Held, Young, and Mansbridge, to determine which groups need to be included to ensure that a process is democratic:

- 1) Is there a group whose life chances are affected by the decisions to be made?
- 2) Is this group situated differently from other groups such that its experiences and understandings of the issues at hand are unlikely to be included in deliberations?
- 3) Is it likely that the group's interests will be meaningfully included in decision-making if they do not have specific representation?
- 4) Do group members trust the existing decision-making bodies to take their concerns into consideration equally with the concerns of others?
- 5) Has the group been previously viewed by dominant groups as incapable of meaningful participation as political equals?
- 6) Will the decision-making body address emerging issues on which the group's positions have not yet crystallized?

These six questions can guide both marginalized groups seeking representation and people involved in current decision-making processes to identify when marginalized groups ought to have specific representation and, further, when that representation ought to come specifically from groups members rather than outside representatives. That is, that inclusive representation is a process for people significantly and specifically affected by

decisions that will be made, who are situated differently from other members of the politically community such that the group's views are likely to differ from other groups and the group is unlikely to be heard without specific representation. In addition, representation by a member of the group is called for to address the effects of power dynamics that have traditionally subordinated the needs of marginalized group to those of others in the political community, including lack of trust in governing bodies by marginalized groups and social biases that have normalized marginalized groups' exclusion from power. Finally, representatives from marginalized groups are needed to ensure the group is well represented when new and unexpected issues arise; issues on which a community could not brief their representative ahead of time.

### ***Summary***

The greater inclusion of marginalized people in decision-making that affects them can clearly be defended as a social justice concern. The question explored here is whether this inclusion enhances or contradicts democratic principles. Inclusive representation can provide marginalized groups with greater influence on local or global decisions than they would have through majoritarian or other established procedures. The basic concern is that this increased influence might harm members of majority groups, or, of more troubling concern, other oppressed groups such as women or the poor who are among the dominant ethnicity, by reducing the amount of control they have over decisions.

To examine this question, three conceptions of global democracy are proposed, each focused on a different, but critical, democratic principle: Democracy is a concern for states who determine, for themselves, how to bring forward their citizens' concerns to the global sphere; a global public sphere is created where groups of people can seek recognition when

other democratic processes have failed to provide them with a meaningful voice in decisions that affect them; and global decision-making bodies are established that ensure groups that are affected by their decisions experience equal respect and concern, especially when these groups are otherwise marginalized. The challenge for advocates for more inclusive democracy is to find ways to balance the underlying principles of each. Inclusive processes for representative seek to create this balance by crafting ways for those who are excluded from the attention of local and state decision makers to access public spheres and decision-making bodies.

Inclusive processes can be criticized on three levels: that they are anti-democratic for amplifying the voice of marginalized groups; that they are anti-democratic for enhancing the influence of marginalized groups; and that they cannot be created in ways that meet democratic goals without becoming so large that they cannot act. However, when democracy, in its essence, is seen as the demonstration of equal respect and concern for each person within the political community, then inclusive processes can be supported as legitimate, even necessary, democratic remedies for undemocratic political situations. Processes designed to increase the voices of marginalized people protect against the silencing of disliked minorities and offer access to more relevant information in decision-making. Processes created to increase the influence of marginalized people assure the equal status, through equalizing access to the power to shape policies, despite prejudices by majorities. Without the assurance of decision-making power over the issues that affect them, marginalized people are forced into a childlike position in relation to states and dominant groups: decisions are made for them by others and they are, in essence, ruled by the majority. Finally, crafting inclusive processes designed to meet the first two democratic

challenges is possible when the focus is placed on the inclusion of those who are directly affected in significant ways by the decisions that will be made and who are persistently excluded from effective participation in decision-making within normal channels because of biases against them by members of the dominant or majority group.

In July 2012, women from the Center for Health and Gender Equity (CHANGE) held up a sign at the XIX International AIDS Conference, held in Washington D.C., that illustrates the importance of inclusive processes for meaningful influence in decision-making. The sign read: "Including women means: not just having us at the table but allowing us to call the meeting." To paraphrase Dworkin, when processes are found or invented that do a better job of ensuring that every person involved enjoys equal status in the crafting of decisions that affect them, then there cannot be opposition to these processes on democratic grounds. Instead, these inclusive processes should be welcomed for their potential to enrich existing democratic practices.

### CHAPTER 3 THEORETICAL FOUNDATIONS FOR THE REPRESENTATION OF MARGINALIZED GROUPS

We can no longer pretend that the full range of ideas and preferences and alternatives has been adequately represented when those charged with the job of representation are all white or all male or all middle-class, or that democracies complete their task of political equality when they establish a free market in political ideas. Anne Phillips (1996, 151)

It is not people's identity as such that seeks for representation, but their ideas and claims as citizens who suffer, or are liable to suffer, injustice because of their identity. Nadia Urbinati (2000, 776)

Efforts to apply concepts of political representation to civil society and the global sphere of activities are relatively recent (see Warren & Castiglione 2004). However, theoretical and empirical work focused on representation, specifically on how it ought to be structured to ensure the inclusion of various interests, has a long history within political science. Attending to the work in this tradition can inform attempts to expand representation to global and to groups frequently left out or made invisible in decision-making processes that affect them.

This chapter proceeds in three sections. First, I describe the primary categories developed by Hannah Pitkin (1967) for analyzing the role of the political representative: these categories provide a useful foundation for understanding the purposes of setting up representational processes and for identifying potential gaps or weaknesses that might affect marginalized groups when these processes are established. Next, I draw on Pitkin's foundational work on political representation to make an argument that political representation is best understood as legitimacy in decision making for others. In this section, I examine changing ideas about the purpose of representation and who the people are that ought to be represented. This argument leads into the third section, in which I

document further changes to the theory and practice of representation: non-elective representation in the global sphere.

### ***Types of representation***

In 1967, Pitkin's analysis of the differing conceptualizations of what representatives were supposed to be and to do led her to identify four categories of political representation: formal, descriptive, symbolic, and substantive. These categories have shaped subsequent approaches to political theories of representation. Although Pitkin's focus was broader than the attention this project gives to the political representation of marginalized groups, her categories are, nonetheless, instructive. Each category highlights a different approach to the meaning, functions, and processes for legitimation, of representation. As calls for representation expand into new spheres of decision-making, Pitkin's categories are useful for thinking through how these representation processes might be structured. Pitkin describes these as four distinct theoretical categories; however, they are not mutually exclusive either in theory or in practice.

Formal representation is concerned solely with processes: specifically, those processes put in place for authorization or accountability. So long as a representative is either selected or subject to removal according to an established, accepted process, the representative is considered a legitimate stand-in for her constituents. In formal representation, what the representative actually does in the process of representing is not a concern. This form of representation can be the easiest to institute and evaluate because the focus is on the process and not the outcomes of decisions.

Symbolic representation refers to the meaning that a representative holds for her or his constituents. As with formal representation, what the representative does is not a

concern in symbolic representation. Rather it is what the existence of the representative “suggests, evokes, [or] implies” to constituents that matters (Pitkin, 1967, 97). Frequently cited early examples of symbolic representatives include the Queen of England or the Pope. More recent studies of political representation have greatly expanded Pitkin’s description of symbolic representation, such as examining the symbolic effect that representatives from marginalized groups have for group members. For example, Theobald & Haider-Markel (2009) use the framework of symbolic representation to examine ways in which the existence of public officials and legislators from minority groups suggests a multiracial democracy and the equal citizenship of minorities in the population.

Substantive representation is focused on the outcomes of representation, rather than the processes. What matters for this form of representative is that she or he represents the needs and interests of the group, as best those can be defined. Substantive representation is said to occur when the representative first and foremost acts for the wellbeing of the group, whether or not the group’s interests are articulated directly by the group or are perceived by the representative. How the representative was selected or can be removed and to which groups the representative belongs are immaterial for substantive representation.

Descriptive representation occurs when representatives are required to be members of the group they represent. Mansbridge (1999) defines descriptive representatives as “individuals who in their own backgrounds mirror some of the more frequent experiences and outward manifestations of belonging to the group” (628). This would be the case when, for example, a governing body sets criteria that the representative for a group of Indigenous people must come from that Indigenous group himself.

Although Pitkin described these categories as four different categories of representation based on different logics and appearing in different circumstances, expectations for representatives frequently combine elements of two or more of these categories. Most obviously, formal and substantive representation are combined in an image of representation that includes both the sense that legislators ought to be formally selected and held accountable through elections and that they ought to provide substantive representation while in office. When attention turns to representation of marginalized groups, descriptive and symbolic types of representation are often highlighted, without considering the ways in which these forms of representation can alternately enhance or limit the accountability and substance found at the center of the other two categories.

In practice, each category of representation contains elements that are important and interconnected with elements of the others for the representation of marginalized groups. The rules of *formal representation* require that transparent processes be in place that allow the represented to select or recall (or both) their representatives. Establishing these processes creates particular challenges for marginalized groups, such as Indigenous peoples, who frequently are divided by state borders, and those, such as many communities affected by HIV, who are criminalized based on their identities or behaviors. The concept of *symbolic representation*, when applied to marginalized groups, draws attention to the important role representatives play as public faces of the group. For members of the marginalized group, a representative symbolizes a level of acceptance as equal members of the larger community. Within a decision-making body, representatives of dominant groups may view the physical embodiment and actions of representatives of marginalized groups as symbolizing all the other members of the group. Similarly, the



general public may judge the entire group based on what the representative says or does. At the same time, the presence of marginalized groups at decision-making tables symbolizes to non-group and group members alike that the group is now part of the governing body. *Descriptive representation* draws attention to questions of whether representatives ought to be members of the group they represent and, if so, whether that might create other effects, positive or negative, for the group.

The goal of representation, with these three forms at its service, is *substantive representation*. Substantive representation occurs when constituents' interests, the *substance* of their political will, are advocated for, alongside others' interests, in political decision-making. Although there are many ways that representatives might go about doing this, at a minimum, this means that some kind of collective identity is required for the members of marginalized groups and some kinds of communicative practices between representatives and constituents must exist, despite any legal vulnerabilities (such as criminalization), resource challenges, and geographic differences.

For each of these categories, and most of the early theoretical work on representation, the thorny question of what it is that representatives are actually supposed to do to make their constituents – or their constituents' interests – present is left largely unsolved. Edmund Burke is the exception. His eloquent defense of the representative as a trustee for constituents' interests, made in his *Speech to the Electors of Bristol* (1774), outlined two distinct methods for engaging in the work of representation. The first method, strongly opposed by Burke, is that of a delegate. The delegate takes his instruction directly from his constituents to the legislature, voting exactly as constituents instruct him to do. In the delegate model of representation, deliberation happens among constituents. Once their

decision is made, the job of their representative is to support and advocate for that decision. The second method, and the one with which Burke identifies himself, is that of a trustee. Representatives who operate as trustees commit to hearing and respecting the opinions of their constituents but they do not bind themselves to voting exactly as their constituents' wish. Burke says of the representative, "his unbiased opinion, his mature judgment, his enlightened conscience, he ought not to sacrifice to you, to any man, or to any set of men living" (447). In the trustee model of representation, the critical deliberation happens among representatives in the legislature. There, the representative must use her knowledge of her constituents' situations, her understanding of the consequences of different courses of action, the information she learns from other representatives, and her wisdom to make decisions that are in the interests of her constituents and the good of the entire polity.

***Representation as legitimacy in decision-making for others***

In Pitkin's close linguistic and functional analysis, she highlights a fundamental tension in the concept of representation. Close examination of this tension opens new directions for thinking about representation in non-elective settings. Pitkin defines representation as "the making present of something which is nevertheless not literally present" (Pitkin, 1967, 144). Most subsequent work on representation focuses on the first part of the equation: the person who "makes present" the others. However, the second part of the equation is equally important because it directs our attention to those people or interests that are "not literally present"; highlighting the absence of some other group of people than those who are seen. Instead of being distracted by those we see at decision-making tables, the question arises: who is not here? Further, attention to the second half of

the equation reveals the fact that a decision is being made whenever representation is performed. This decision holds, first, that there is someone that ought to be made present, and second, that political representation is the correct process for accomplishing this. Making visible both aspects of this decision opens conceptual space for the investigation of new forms of political representation.

***Changing ideas about what ought to be “made present” by the representative***

Pitkin’s definition of representation as “making present” something that is not actually present has been enduring. It fits the way representation is and has been constructed. Never set in stone, however, is what exactly it is that calls out to be made present. Current claims for representation within global fora and for groups that have been historically excluded from decision-making power, are the most recent challenges to a system that has been pressed constantly to expand and change. Individuals, social groups, interests, and discourses are variously highlighted as the appropriate elements of representation. Modern representatives are generally described by liberal democratic theorists, and in common usage, as representing their individual constituents. Robert Dahl (1989, 2006) typifies this focus, as does Jeremy Bentham ([1907] 2007) in an earlier time. Current theorists concerned about political exclusion and inequalities, including Iris Marion Young (1989, 1990, 1993, 1996), Melissa Williams (1995), Anne Phillips (1996), Jane Mansbridge (1999), and Nadia Urbinati (2000), expand the earlier focus on individuals to include the social groups to which they belong. An older tradition, exemplified by John Stuart Mill (1861) and Edmund Burke ([1775] 1854-56), purposes representation as the bringing forward of relevant interests. Fundamentally, these elements are all based in the logic of representation of people: whether as individual choosers of preferences and

bearers of interests or as members of identity groups that are effectively excluded from democratic processes because of social bias.

Representation, as Pitkin so aptly describes, contains multiple requirements within itself that are at times in tension with one another. At the risk of oversimplifying a sometimes fraught concept, each of these different focus areas provides a different pathway with which to approach the same multi-faceted concept. All of these approaches, whether focused on individuals, groups, or interests, portray representation as legitimate when it is perceived that the representative “makes present” the issues and wishes of the correct group of persons: those whom current norms regard as the constituents for whom the representative is expected to speak.

In this overview of the landscape of political representation, one sees two overlapping groups: constituents and representatives, with representatives generally coming from the constituent group. I would suggest that there is another important group, an audience, that plays a significant role in determining who are legitimate bearers of interests and what are legitimate interests to bear. The audience sees and judges the composition of the decision-making body and the outcomes. Constituents are part of the audience, but the audience is larger than constituents. It also includes those who are affected by decisions but unable to play a role in the selection of representatives, such as children, resident alien immigrants, those in a perpetual losing minority, or those outside of the jurisdiction for voting purposes but affected by decisions nonetheless. The audience also includes those outside the jurisdiction who are not materially affected by decisions but who do use moral criteria to judge whether the decision-making body is properly constituted and discharging its duties fairly.

Closely linked to judgments about whether representation has been legitimately instituted within a political system is the social perception about which groups have interests that are real, valid, and different from those already represented. No matter what the setting in which representation takes place, from legislatures to governing boards, this social perception should be understood as a kind of “common sense” among the audience for the decision-making body. As Gramsci (1971) explained, what the audience believes is natural and normal -- that is, common sense -- will largely match the status quo and preferences of current dominant groups. Understood this way, marginalized groups must struggle to get other members of the audience to believe, instead, that it is natural and normal to support the inclusion of their interests alongside those of others in decision-making bodies.

***Representation as making interests present***

In established democracies, the right to vote was once reserved only for those who are seen as having particular economic interests. This is no longer the case. Indeed, while representation of interests continues to hold significance for our sense of whether or not a decision-making body is adequately constituted, ideas about which interests require representation have broadened. Imagine, for example, an election in a racially-diverse state in the U.S. in which all the members elected to office were white heterosexual upper class men. There are no quotas or affirmative action requirements in the U.S. for political parties or legislatures, so no challenge to this situation could be brought formally. However, as quoted by Phillips (1996) earlier, this situation strikes us as unfair, as unrepresentative. This situation would become a matter of public concern, with open arguments made about the legitimacy of a legislature with no members who were racial minorities or women of

any race. This thought experiment demonstrates that there is some recognition among members of the political community that racial minorities and women from all races may have particular political interests that are not likely to be represented by a body entirely composed of white men. However, it is unlikely that any action to protest the lack of representatives who were poor people or lesbian, gay, bisexual, or transgendered would gain similar traction, even among the poor or LGBT communities, as members of these groups do not expect (yet) to be seen as deserving of representatives from their communities or as groups who have the power to challenge the legitimacy of a governing body by their absence. The point is that which interests are perceived as legitimate and which groups are considered able to speak for those interests varies and, further, that dominant groups often are seen as capable of representing all people in a way that marginalized groups are not.

Classical political theorists conceptualized diversity of interests, for purposes of governance, largely in terms of class or economic divisions. Plato ([380 B.C.E.] 2004) and ([350 B.C.E.] 2009) expressed concerns about the injustice of rule by factions, conceived as rule by either the rich for the rich or by the poor for the poor, and about the destabilizing effects of economic inequality. Aristotle, in *Politics*, notably hailed social structures that largely consist of and are governed by what we would now call the middle class, a group marked by neither the insecurity of poverty nor the excesses of wealth. For Aristotle, this created shared interests and, therefore, a situation in which political friendship can thrive. These classical theorists saw diverging interests as dangerous, centering their political calls on the need for structures that create unity above all else.

Later, social contract theorists presented contrasting views on the question of whether unity of interests is necessary for the legitimacy of a political system. For Hobbes ([1651] 1994) and Rousseau ([1762] 1988), unity of interests formed the bedrock of the social contract. For Hobbes, unity was created through the shared experience of human vulnerability and the near-exclusive claim to power of the sovereign or monarch; in this view, other kinds of differences are not relevant at best, and their recognition, let alone their representation, could be deadly for human security. For Rousseau, the common interest was the *raison d'être* for the social contract and the only legitimate laws were those dealing with shared interests. People would have their own interests; but would be expected to vote based on their best sense of what was for the good of all. Like Aristotle, Rousseau was concerned about the divisive effects of differing economic interests among citizens, and was, therefore, a proponent of greater equality. Locke ([1689] 1980) was not concerned with unifying the interests of individuals, but rather with legitimizing a system within which people were free to pursue their own individual interests with the least interference by others or the state. Locke, the founder of classical liberalism, justified economic inequalities through their relationship to property and did not appear to find inequalities to be an issue of major concern for the governance system.<sup>9</sup>

Marx (1844, 1871), by contrast, was not afraid that recognition of differences could bring bad consequences; rather his concerns centered on the dangers in the *lack* of

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<sup>9</sup> Waldron (1979) presents a convincing response to this common interpretation of Locke's views on property and inequality. In Waldron's reading, Locke establishes, in the *First Treatise of Government*, that natural law gives each person both the right and duty to preserve himself, first, and then others in need. The duty to others includes Locke's assertion that each person, when partaking of the earth's resources, must make sure that he leaves "enough and as good" for others. Once the social contract has been entered into, as described in the *Second Treatise of Government*, this duty to others becomes the responsibility of the government.

recognition of conditions of privation and exploitation. However, Marx's political thought does not recommend class-based representation in the political system. His adamant belief that economic exploitation of individuals could -- and would -- end meant that class interests were temporary and appropriately weighed only when they were the interests of the workers. Like Rousseau, Marx sought a unified political system, devoted to the good of all. For Marx, the only pathway to this end was through ensuring that everyone was a producer (to the extent they were able), thus ending class-based distinctions.

In the early days of the U.S. republic, class differences also received close attention. This is clear from Madison's writings, as Publius, in the Federalist Papers 10 (1787) and 51 (1788), published to encourage support of the newly drafted U.S. Constitution. However, Madison's concerns centered on the maintenance of political unity and careful management of differences to ensure that widespread democracy would not threaten the economic standing of landowners and businessmen.

There is no meaningful space within the work of any of these early political theorists for attention to particular burdens that might be placed on minorities by majorities or to forms of domination based on culture, religion, or other social practices, including that enacted within families. Indeed, for these earlier theorists, representation of interests, when considered acceptable at all, was perceived as representation of economic or material interests. Further, this representation was limited, without apparent recognition of this as a limit, to the kinds of activities that male heads of households might pursue.

Another set of political philosophers, however, did concern themselves with more nuanced questions about which interests should be included in a representative body. Burke (1774a, 1792) and Mill ([1861] 2008), despite many philosophical differences, took



this approach. This approach is also taken by Yates (writing as Brutus, 1787) and Hamilton (writing as Publius, 1788) in their arguments on either side of the debate over ratification of the U.S. Constitution.

For Burke, what was most important was that, with rare exceptions, one's community's industry interests were represented (i.e. manufacturing, agriculture, fishing, or shipping). If all industry interests were represented, then so were all communities, even those with no vote. Burke understood this as "virtual representation"; which he described as "that in which there is a communion of interests and a sympathy in feelings and desires between those who act in the name of any description of people and the people in whose name they act, though the trustees are not actually chosen by them" (1792). The concept of virtual representation fits cleanly with Burke's ideas about how representatives ought to operate within legislatures. So long as it is interests that one must bring forward for deliberation, rather than the specific wishes of particular groups of people, then the trustee relationship between representative and constituents can function.

When Burke argued that American colonists (1774a) and Irish Catholics (1792) ought to have representatives in Parliament, it was not because he thought that American colonists or Irish Catholics required a physical presence in the legislature in order to be represented. Rather, he saw their interests as different from any currently represented in the legislature and, therefore, needing inclusion in Parliamentary deliberations. Presumably, if there were some way to make present their interests through an existing representative, that is, through "virtual representation," Burke would have been satisfied.

Burke's discussion of discrimination against Irish Catholics is notable for his recognition of social and psychological issues that affect the ability for Protestants to

represent their interests. Once he turned to this question, he made no mention of the industry interests that are central to his theory of representation elsewhere. Indeed, he underscored the extent to which he believed virtual representation would be impossible because of biases held by Irish Protestants toward their Catholic compatriots:

Sure I am that there have been thousands in Ireland who have never conversed with a Roman Catholic in their whole lives, unless they happened to talk to their gardener's workmen, or to ask their way, when they had lost it in their sports—or, at best, who had known them only as footmen, or other domestics, of the second and third order: and so averse were they, some time ago, to have them near their persons, that they would not employ even those who could never find their way beyond the stable. I well remember a great, and in many respects a good man, who advertised for a blacksmith, but at the same time added, he must be a Protestant. It is impossible that such a state of things, though natural goodness in many persons will undoubtedly make exceptions, must not produce alienation on the one side and pride and insolence on the other (1792).

On the question of representation of Irish Catholics, Burke went on to write, “[a]s things stand, the Catholic, as a Catholic, and belonging to a description, has no virtual relation to the representative—but the contrary.” Indeed, Burke made his feelings clear that virtual representation was often preferable to a direct constituent-to-legislator relationship; however, without a “communion of interests and sympathy,” the very position within which marginalized groups find themselves, virtual representation would be impossible.

Subsequently, the idea that the legislature ought to be based on representation of interests, albeit with an explicitly elitist twist on Burkean virtual representation,<sup>10</sup> was

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<sup>10</sup> Burke is well known for elitist statements about the existence of a “natural aristocracy” whose members ought to be elected to Parliament. Nonetheless, as compared with Hamilton, there is nothing in his writings about virtual representation to suggest that working class people qua working class people should see themselves as represented by this natural aristocracy, neither through “a sympathy of feeling” or “community of interest.” However, this does not mean that Burke calls for specific representation for working class

expressed by Hamilton. In the Federalist Paper No. 35, Hamilton (1788, writing as Publius) recognized that ratification opponents were concerned that the legislative branch would be too small to adequately represent the interests of all voters. He argued that there were three main interests that needed to be part of the legislature, and that electoral processes would naturally put members of these groups into office: merchants, members of the learned professions, and landed interests. Further, Hamilton argued further that these groups were well placed to look out for less advantaged or informed groups connected to them, with, for example, merchants looking out for laborers, landed interests looking out for small property holders, and the more educated members able to critically analyze laws and policies for everyone.

The arguments put forward by Yates (1787) to oppose ratification of the U.S. Constitution articulate a nuanced-understanding of the multiplicity of interests within the political community and stand in direct contrast to Hamilton's elitism. Yates, writing as Brutus (Brutus, No. 3), argued that representatives "should bear the strongest resemblance of those in whose room they are substituted" and "to have a proper representation...each class [of people] ought to have an opportunity of choosing their best informed men for the purpose." His critique of the proposed lower house of Congress stands in opposition to what Hamilton would write in response -- that the elites in a given area will naturally be best placed to represent everyone.

The great body of the yeomen of the country cannot expect any of their order in this assembly — the station will be too elevated for them to aspire to — the distance between the people and their representatives, will be so very great, that there is no probability that a farmer, however respectable, will be chosen — the mechanicks of every branch, must expect to be excluded from a

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interests. Rather, it would seem that, for Burke, workers would be viewed as represented based on the industry interests of their communities.

seat in this Body — It will and must be esteemed a station too high and exalted to be filled by any but the first men in the state, in point of fortune; so that in reality there will be no part of the people represented, but the rich, even in that branch of the legislature, which is called the democratic. — The well born, and highest orders in life, as they term themselves, will be ignorant of the sentiments of the midling class of citizens, strangers to their ability, wants, and difficulties, and void of sympathy, and fellow feeling (Federalist No. 35).

Throughout Brutus No. 3, the kinds of resemblances that Yates highlighted as important foreshadow Mills in their breadth: sentiments, opinions, feelings, occupations, wants, and interests.

For Mill (1861), the widest possible range of interests called for representation. For Mill, as for Burke, a primary value of the legislature was found in its creation of a deliberative space. The greatest diversity of ideas and opinions had to be included within legislative decision-making to ensure that all possibilities, including creative new ones, and their effect on people's welfare, were considered. It was crucial for Mill that all relevant interests be included; otherwise the deliberation would lack the required data for informed decisions. Unlike Burke, however, Mill advocated for a broadly inclusive political system based on representation of individuals and their interests.

Because of his concern that the widest variety of people and their interests be represented in the legislature, Mill was a proponent of a ranking form of proportional representation, in which voters would order their ballots according to their preferences. The result, for Mill, should be the inclusion of "all interests or classes of any importance" (1861, 125). The concern that an assembly with the broadest representation of interests possible would find it difficult to make decisions was not particularly troublesome for Mill, as he felt the important goal for an assembly is to deliberate and then to delegate work to

the people it feels appropriate. Although not labeled as such, virtual representation, specifically for women, rears its head in Mill's theory as well. Despite his advocacy for the rights of women in some respects, Mill did not see the need for women representatives in the legislature. Because Mill viewed representation as based on interests, rather than individuals, and he believed women's interests were identical to those of their male family members, he argued that women were represented adequately by people selected by men.

In a more recent contribution to theories of representation, Plotke (1997) has called for a return to representation based on interests. He argues that formal representation was valued because of the particular context of the Cold War when it was advantageous for western powers to label countries with competitive election processes as democratic and those without as undemocratic. In Plotke's view, the focus on individual constituents, and their ability to participate in formal representative processes (that is, to authorize and hold accountable representatives) has outlasted its usefulness in the current globalized world.

Three important concepts for representation of marginalized groups can be identified in the work on interest-based representation: First, a focus on the inclusion of all relevant interests provides opportunities to argue on behalf of the inclusion of interests of people who are not currently part of decision-making bodies.<sup>11</sup> Second, systems of representation centered on interests can be created that are not reliant on formal authorization and accountability processes to be considered legitimate, something quite useful for creating representative processes at non-state levels where groups who seek inclusion may exist across borders and may face legal barriers to organizing in traditional

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<sup>11</sup> However, this begs the question of how those interests would be determined without the physical presence of marginalized groups. In this way, a focus on representation of interests for people in marginalized groups leads toward a focus on the representation of people themselves.

ways. If it can be instituted adequately, “virtual representation” might provide a way to bring relevant interests into decision-making at global levels. Third, as Plotke’s work makes clear, the legitimacy of different systems of representation is related to the period of time and geopolitical context. This applies to the whole universe of representation options, not just to interest-based representation. An understanding that what is seen as legitimate representation can change over time should allow greater flexibility for change and experimentation to meet current representation needs. This is particularly important as the arenas for representation expand from legislatures to global institutions and organizations.

Where theorists of interest-based representation falter is in the failure to recognize that power struggles determine which interests are seen as valid. Indeed, as Lukes (2005) illustrates, dominant groups are largely able to determine which interests are seen at all. This is the warning raised by Yates in 1787. For members of marginalized groups to get their concerns into a public space where they can be contested is a step forward, although it certainly may not feel that way for the people whose right to even have interests is debated by people outside their group. We cannot claim that all relevant interests are represented within a decision-making body until that determination is made by people from all affected communities and walks of life. Representation of interests, then, becomes based in representation of groups that might have a stake in the outcome. Laclau and Mouffe (2001) highlight the eternally contested nature of every political process, particularly as it relates to inclusion, whether of interests or of groups. Their work on radical democracy offers a reorientation for all marginalized groups from fighting for inclusion to recognizing that inclusion is an on-going struggle. This struggle is for the

group's entry into arenas of power traditionally inhabited by dominant groups, but is not only located there. The struggle continues within the group, as those subordinated within the group, who, depending on the group, might be women, young people, racial or ethnic minorities, religious minorities, or lesbian, gay, bisexual, and transgender group members, continue to fight to have their voices heard. Mouffe (1996) contends that there are so many marginalized groups of people in every level of society that winning one battle for recognition means simply that the next one can be engaged.

In addition, a serious challenge to basing representation solely on interests comes from Phillips (1996). She contrasts a focus on the inclusion of a diversity of ideas, thoughts, beliefs, and opinions, that is, a diversity of the things to which people subscribe, with a focus on who it is that does the representing, that is, a diversity of who the representatives are. Phillips argues that "when the politics of ideas is taken in isolation from what I will call the politics of presence, it does not deal adequately with the experiences of those social groups who by virtue of their race or ethnicity or religion or gender have felt themselves excluded from the democratic process" (141). That is, interest-based representation alone does not solve problems related to agenda setting, equal treatment as citizens, alienation from government or decision-making bodies, or misperceptions by members of privileged groups about the capacities of marginalized groups to participate in self-government. For this, we need to turn our attention to representative processes focused on ensuring that those persons affected by decisions are made present within decision-making processes.

### ***Representation as making people present***

There has been a fundamental shift in political theory, primarily since the late 1980s, away from a focus on what is to be represented (interests) toward questioning who

needs to be at decision-making tables in order to ensure that people affected by a decision, whether the citizens of a state or a newer body created for global decision-making, are represented in the process and outcome. This change has been characterized by attention to the inclusion of women, racial and ethnic minorities, with some small pockets of concern about representation for lesbian, gay, bisexual, and transgender citizens.

The idea that the people have a right to participate in the decisions that concern them has never included all of the people. Beliefs about whether or not one ought to have a say has depended on whether one is seen as fit to speak on one's own behalf and whether one is perceived by the larger society as having interests that are real and valid. In terms of voting, the right to choose one's representatives in government has been limited consistently by whether one is part of a group whose members are seen by socially powerful actors as fit to articulate their own interests and advocate on their own behalf. In some cases, this is based on arguments that some lack the capacity to vote, for example, children (albeit temporarily) and people with severe disabilities are denied the right to vote. On this same basis, women and racial and ethnic minorities have been denied the right to vote (as women continue to be in Saudi Arabia) and people who are currently incarcerated or who have a felony conviction in their past are disenfranchised, and therefore, de-represented, in some places (including ten states in the U.S. that bar some or all of those with a past felony conviction from voting).

Ideas about the right people who ought to have a voice in decision-making have changed substantially over time. Certainly we have come far since Wollstonecraft was obliged to argue in 1792 that, "Women ought to have representatives, instead of being arbitrarily governed without any direct share allowed them in the deliberations of



government”(chapter 9, para 22). People labeled unfit in the past have won the franchise (the poor, women, racial minorities); people said to not have their own particular and valid interests are widely recognized to have legitimate interests after all (these same groups). Even when groups are recognized as having legitimate and particular interests, historic disenfranchisement has led to on-going marginalization marked by fewer representatives in legislative assemblies and continued low levels of social power. By contrast, groups that have historically dominated political decision-making continue to be overrepresented. The chasm between formal political equality and the unequal composition of legislative bodies challenges the democratic legitimacy of the decisions that are made -- for those who do not see themselves represented, for those who are concerned with full and inclusive deliberations about decisions, and for democratic and critical theorists (see Williams 1995, Young 1990, 1996).

The particular questions being asked about representation have expanded over time as democratic language has been applied more widely, to more groups, situations, and types of places. In 1967, Pitkin largely dismissed the concept of descriptive representation as unable to provide any guidance about what a representative ought to do. Further, concerns are absent in Pitkin’s work about political inequality and the lack of access to meaningful representation for disliked groups, possibly leaving little reason for her to consider potential uses for descriptive representation. Contrast this with Williams, writing three decades later, who claims, “how we conceive of the social groups that are relevant for politics radically affects our conclusions about what constitutes fair representation” (1995, 30). Because of the emergence of works by Mansbridge (1983, 1999, 2003), Young (1989, 1990, 2000), Phillips (1995, 1996, 2000, 2003), and Williams (1995, 1998), contemporary

representation theory has focused largely on the inclusion of previously disenfranchised groups.

### ***Political representation in global arenas***

From before the founding of the League of Nations until recent times, representation in venues dealing with global governance was viewed strictly as the prerogative of states. The lines of authority were simple and clear: governments were responsible for representing the people within their state boundaries. If governments failed to represent some of the people, then recourse for those people existed only within the hope that some other government would take their plight to heart and speak for them. This might happen, for example, for national minorities living within one state but sharing an ethnic, or “national,” identity with the dominant group within another state. Even in these cases, people could expect advocacy on their behalf by another state only if such advocacy aligned with state’s strategic interests.

The United Nations, like the League of Nations before it, was founded on principles of state sovereignty. The United Nations charter and, indeed, its very name, point to the purpose of “developing friendly relations *among nations*” (Chapter 1, Article 1.2, emphasis mine). This focus on sovereignty has led to tension in current times: between, on the one hand, the desire to hold leaders accountable for killings, torture, and policies that undermine the social fabric of existence for people within their countries and, on the other, the wish to ensure that states do not trample on the existence of other states, and their peoples, simply because they are bigger, richer, or more powerful in some other way. The focus on state sovereignty that underpins the structure of the United Nations functions as a barrier between states to engagement in one another’s internal policies: treating each state as the

equal of every other in decision-making and allowing intervention into a state's affairs only under the strictest of conditions.

The dilemma that has arisen is this: what happens to groups of people whose governments, responding to domestic animosity against them (whether by members of dominant domestic groups, people serving within the government itself, or both), persistently ignore their needs or actively work to make their life chances and conditions unbearable? There is little chance that governments that neglect or oppress groups of people at home will vigorously advocate for these same people in global arenas.<sup>12</sup> Domestically oppressed groups can hope, like national minorities, that some government other than their own might feel a sense of kinship with them and see strategic value in pressing for their rights or wellbeing. However, when the same groups are marginalized in country after country, as the past experiences confirm for many groups -- including Indigenous Peoples, lesbian, gay, bisexual, and transgender people, people living with HIV, and others -- the chance that their needs will be championed at global levels appears quite dim. Even dimmer are prospects that such attention would trickle back down to affect their experiences at the state level.

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<sup>12</sup> Notwithstanding the language in the *Declaration on Principles of International Law concerning Friendly Relations and Cooperation among States in accordance with the Charter of the United Nations* (the "Friendly Relations Declaration," UN Resolution A/RES/25/2625 1970) within which states are responsible for "representing the whole people belonging to the territory without distinction as to race, creed or colour," in practice, those groups that are marginalized domestically receive little concern by their governments in global fora, except when it serves the governments. For example, from 2010 to 2013, China sought to burnish its human rights record through attention to its HIV epidemic (Global Fund 2012, Xinhau 2013). The fact that China's efforts turned out to be more symbolic than meaningful lead to speculation that the real goal for China was to enjoy rehabilitated image that would be demonstrated by selection to the UN Human Rights Council (Hayoun 2013). China was selected for membership on the UNHCR for the 2013-2016 term. However, the Chinese government has continued to violate the human rights of people living with HIV and organizations seeking to stem the epidemic (Yu 2014).

Nevertheless, shifts have occurred in the practices of global representation. These shifts are characterized by an acknowledgement, stated or unstated, that some groups may have the right to represent themselves within global decision-making. As Warren and Castiglione (2004) note, “the United Nations has begun recognizing civil society organizations within its programs as representative of groups *that are not well represented by its member states*” (404, emphasis mine). While governments continue to be the overwhelming voice in global governance,<sup>13</sup> these shifts represent small movements away from the idea that governments are the only legitimate decision makers. Chief among these movements are the processes that involve the participation of the two groups described in this project: those by and for Indigenous Peoples and by and for people living with HIV and key affected populations. These movements were similar in that both occurred during a time in which arguments for the democratic value of civil society movements were highlighted in political and academic realms, especially as formerly autocratic states in Eastern Europe and Latin America transitioned to democracy. Yet, the processes by which they reached global recognition were conducted separately from each other. The frameworks for participation that were developed as a result of their respective movements for recognition also differ: Indigenous Peoples movements succeeded in getting governments and global bodies to agree that the “free, prior, and informed consent”

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<sup>13</sup> The strongest non-government players in shaping global and national conditions and policies continue to be multinational corporations; however, corporate interests lack a *formal* role in global governance. While considerable, their influence is enacted through the pressure they place on, and an alignment of interests with, their governments and governments of the world and through their ability to create economic conditions to which governments must react. My focus here is on marginalized groups, whose very marginalization means that they lack access to the powerful venues for influence that others, such as corporate interests, enjoy; yet, at least two of these groups have won formal recognition within global governance processes of a right to participate directly in decisions that affect them.

of Indigenous Peoples was needed before engaging in activities that would affect them (ILO Convention 169, UN Declaration on the Rights of Indigenous Peoples); while people living with HIV achieved support for what is known as the GIPA (Greater Involvement of People Living with HIV and AIDS) principle, by which governments and global bodies commit to “support a greater involvement of people living with HIV at all...levels...and to...stimulate the creation of supportive political, legal and social environments” (from the 1994 Paris Declaration).

The increasing acceptance of the idea that civil society members have an important role to play in global decision-making is illustrated in Table 2. The table shows the many ways that civil society organizations are able to engage with the UN system. It also demonstrates that it is rare that civil society be allowed to select its own representatives in these decision-making processes. Indeed, only Indigenous Peoples and networks of people living with HIV and HIV-related civil society organizations have that prerogative. Further, the existence and timing of a human rights declaration does not appear to have a relationship with the existence of representation in decision-making. Representation can come after relevant declarations call for it, as in the case of people living with HIV, before such declarations, as in the case of Indigenous Peoples, or not at all despite such declarations, as in the case of women, racial minorities, migrants, people with disabilities, or children.

The Committee on the Protection of the Rights of Persons with Disabilities, for example, is one of the bodies on the list that allows engagement by civil society. The International Disability Alliance (IDA), a network of eleven global and regional networks of people with disabilities, identifies multiple challenges for organizations seeking to

influence the selection of members to the Committee. As they explain to their member organizations:

The process which took place at previous COP [Committee of State Parties] elections and experience from other election processes of UN human rights treaty bodies show that the outcome of the election process in New York is strongly connected to the efforts made by permanent missions to the UN in seeking support for their candidate from other States- often in exchange for reciprocal support related to other UN election processes. The quality of the nominees is not always the most relevant criterion for States Parties in taking a decision for whom to vote (IDA 2014, p. 2).

By contrast to the State processes, IDA seeks specific characteristics in representatives: the most important of which they describe as knowledge in the rights of people with disabilities and connections to communities of people with disabilities.

**Table 2: Civil Society Representation in Global Organizations**

<b>Civil Society Group</b>	<b>Global Organization<sup>14</sup></b>	<b>Representation Role</b>	<b>Number of Representatives Selected by Civil Society</b>	<b>Term</b>
<b>Indigenous Peoples</b>	United Nations Permanent Forum on Indigenous Issues (2000)	Advisory Body to the UN Economic and Social Council (ECOSOC). Regional Indigenous Peoples' organizations nominate 8 of the members. Member States select the other 8.	8 Members are selected by civil society	3 years, Possibility of one additional term
<b>People Living with HIV</b>	Programme Coordinating Board (PCB) of the Joint United Nations Programme on HIV and AIDS (UNAIDS) (1994);	Governance body for the Joint UN Programme. Civil society holds five non-voting seats (three for developing countries and two for developed and countries in transition, with a Delegate and an Alternate organization selected for each) alongside 11 non-voting UN Co-Sponsors, and 22 voting Member States. Decisions are made by consensus.	5 Delegates and 5 Alternates	2 years Possibility of one year extension
	Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund) (2002)	Civil society holds three voting seats out of 20 on the Global Fund Board of Directors: one each for the Developing Country delegation; the Developed Country delegation; and the Communities (of people affected by the three diseases) Delegation.  Each of these Delegations selects a Delegate, an Alternate, and a Communications Focal Point. All attend Board meetings but only the Delegate can vote. The Communities delegation has 40 members who are all living with or affected by HIV,	3 Delegates and 3 Alternates	2 years

<sup>14</sup> Founding documents: ECOSOC Res 2000/22 (Permanent Forum); ECOSOC Res 1994/24 (UNAIDS); Global Fund to Fight AIDS, Tuberculosis and Malaria By-laws (2011); ILO Charter (1919); ECOSOC Res 11/2 (CSW); General Assembly Resolution A/RES/2106(XX)A-B (CERD); A/RES/44/25 (CRC); A/RES/45/158 (CMW); A/RES/61/106 (CRPD)

		tuberculosis, or malaria; the Developing Country NGO delegation has 18 members; and the Developed Country NGO delegation has 9 members.		
<b>Workers</b>	International Labour Conference, the governing body of the International Labour Organization (1919)	The governing body is composed of 28 Member States (10 of these seats are held by "States of Key Industrial Importance") and 28 deputies (alternates), 14 representatives each of workers, and 14 representatives of employers. There are 19 deputies (alternates) each for workers and employers.  Member States select the Worker and Employer Members "in agreement with the most representative national organizations of employers and workers."	Zero	3 years
<b>Women</b>	Committee on the Elimination of Discrimination Against Women (CEDAW Committee) (1982)	Expert panel.  No formal representation role for civil society. Civil society members can file reports and give testimony to the Committee.  States that are party to the Convention nominate and select experts to serve on the Committee. The panel of 23 Committee Members may be members of civil society but are not nominated by or accountable to civil society.	Zero	4 years
<b>Racial Minorities</b>	Committee on the Elimination of Racial Discrimination (CERD) (1965)	Expert panel.  No formal representation role for civil society. Civil society members can file reports and give testimony to the Committee.  States that are party to the Convention nominate and select experts to serve on the Committee. Committee Members may be members of civil society but are not	Zero	4 years Possibility of re-election



		nominated by or accountable to civil society.		
<b>Children</b>	Committee on the Rights of the Child (CRC) (1989)	<p>Expert panel.</p> <p>No formal representation role for civil society. Civil society members can file reports and give testimony to the Committee.</p> <p>States that are parties to the Convention nominate and select experts to serve on the Committee. Committee Members may be members of civil society but are not nominated by or accountable to civil society.</p>	Zero	4 years Possibility of re-election
<b>Migrant Workers</b>	Committee on the Protection of the Rights of All Migrant Workers and Members of their Families (CMW) (2003)	<p>Expert panel.</p> <p>No formal representation role for civil society. Civil society members can file reports and give testimony to the Committee.</p> <p>States that are parties to the Convention nominate and select experts to serve on the Committee. Committee Members may be members of civil society but are not nominated by or accountable to civil society.</p>	Zero	4 years Possibility of re-election
<b>People with Disabilities</b>	Committee on the Rights of Persons with Disabilities (CRPD)(2006)	<p>Expert panel.</p> <p>No formal representation role for civil society. Civil society members can file reports and give testimony to the Committee.</p> <p>States that are parties to the Convention nominate and select experts to serve on the Committee. Committee Members may be members of civil society but are not nominated by or accountable to civil society.</p>	Zero	4 years Possibility of re-election

Despite the avenues for participation available to the groups listed in Table 2, a *right* to participation is not generally recognized. As shown in Table 3, only a few civil society groups see a right to participation included in the existing global conventions, treaties, or declarations: Indigenous Peoples and people living with HIV have broad participation rights; migrant workers have rights to participate in local community decisions; and people with disabilities have rights to participate in state policy and legislation.

**Table 3: Civil Society Provisions in Global Conventions, Treaties, Declarations**

<b>Civil Society Group</b>	<b>Major Existing Global Conventions, Treaties, or Declarations</b>	<b>State Parties and Signatories (if applicable)</b>	<b>Agreed Language Regarding Participation Rights</b>
<b>Indigenous Peoples</b>	ILO Convention No. 169 (1989); United Nations Declaration on the Rights of Indigenous Peoples (2007)	22 State Parties  UN General Assembly Declaration	The right to free, prior and informed consent on issues affecting Indigenous Peoples
<b>People Living with HIV</b>	Paris Declaration (1994); Declaration of Commitment on HIV/AIDS (2001); Political Declaration on HIV/AIDS (2006); Political Declaration on HIV/AIDS (2011)	The Paris Declaration was made by 42 States  The other three Declarations were made by the UN Member States during UN General Assembly Special Sessions on HIV and AIDS	The right to participate in decision-making processes that affect the lives of people living with HIV, also known as the GIPA (Greater Involvement of People Living with HIV) principle.
<b>Workers</b>	Freedom of Association and Protection of the Right to Organise Convention, ILO Convention No. 87 (1948); Right to Organise and Collective Bargaining Convention, ILO Convention No. 98 (1949); Workers' Representatives Convention, ILO Convention No. 135 (1971); Tripartite Consultation (International Labour Standards) Convention, ILO Convention No. 144 (1976);	153 State Parties  164 State Parties  85 State Parties  137 State Parties	The right to organize and negotiate collectively without facing discrimination, both for workers and their representatives.  Workers (and workers' organizations) have the right to free and voluntary collective bargaining with employers (and employers' organizations) to determine working conditions and terms of employment and

	Labour Relations (Public Service) Convention, ILO Convention No. 151 (1978); Collective Bargaining Convention, ILO Convention No. 154 (1981)	52 State Parties  46 State Parties	regulate worker/employer relationships.  Consultations are required between workers, employers, and governments, operating on equal footing, on issues related to ILO standards, conventions and agenda items for the International Labour Conference.
<b>Racial Minorities</b>	Convention on the Elimination of All Forms of Racial Discrimination (1965)	177 State Parties  5 Signatories	The equal right to vote and be eligible to be elected and hold public office. The equal right to participate in policy creation and implementation and in non-governmental organizations.  No language provides rights of consultation, involvement, or consent in decision-making that specifically affects racial minorities.
<b>Women</b>	Convention on the Elimination of Discrimination Against Women (CEDAW) (1979)	188 State Parties  2 Signatories	The equal right to vote and be eligible to be elected and hold public office. The equal right to participate in policy creation and implementation and in non-governmental organizations.  No language provides rights of consultation, involvement, or consent in decision-making that specifically affects women.
<b>Children</b>	Convention on the Rights of the Child (1989)  The Third Optional Protocol (adopted 2011, in force April 2014) allows children to directly file a claim with the CRC.	194 State Parties  2 Signatories  14 State Parties  46 Signatories	Individual children have the right to express their views about issues that affect them and to have their views considered, in light of their age and capacity, including in administrative and judicial proceedings.  No language provides rights of consultation, involvement, or consent in decision-making that specifically affects children overall.
<b>Migrant Workers</b>	International Convention on the Protection of the Rights of All Migrant Workers and	47 State Parties  19 Signatories	Rights of consultation or participation by migrant workers and members of

	Members of their Families (1990)		their families in decisions affecting their local communities
<b>People with Disabilities</b>	Convention on the Rights of Persons with Disabilities (2006)	131 State Parties  51 Signatories	In policy and legislation, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

Challenges to the legitimacy of these voices from civil society have been made by government delegations -- at times with some success; but the overall record indicates an expansion, albeit slow, in favor of the inclusion of the voices and perspectives of people who are otherwise marginalized. These challenges can be observed, for example, between the lines of a letter sent to the President of the General Assembly, John Ashe, in January 2014, from the three UN mechanisms designated to ensure meaningful involvement of Indigenous Peoples in global efforts that affect them: the Permanent Forum on Indigenous Issues, the Special Rapporteur for the Rights of Indigenous Peoples, and the Expert Mechanism on the Rights of Indigenous Peoples. In the letter, leaders from the three mechanisms express their disappointment with Ashe's decision not to follow through on commitments for Indigenous participation made in 2013 and requested recognition of their right to fully participate in the convening and facilitation of the World Conference on Indigenous Peoples to be held in May 2014. The authors stressed the importance of their involvement, "It is absolutely critical that all decision related to the World Conference on Indigenous Peoples, its arrangements and the outcome document be made with the full, equal, and effective participation of Indigenous Peoples...and that an Indigenous representative be designated to ensure their participation" (Littlechild et al. 2014). The

authors went on to differentiate their claim for representation from that of other civil society groups, writing “[w]e would like to emphasize that Indigenous Peoples have a status that is distinct from other non-State actors. They are not non-governmental organizations or minorities. As recognized by the United Nations system and multiple other global intergovernmental developments, they are peoples with their own cultures, histories and institutions of authority and decision-making”. Referring to the UN Declaration on the Rights of Indigenous Peoples, the authors describe the “right to self-determination” in terms of “the right of effective participation in all decisions affecting them.” They conclude with reassuring language for governments who might oppose their participation, writing that, “because of [our] unique status, designating an Indigenous representative to work alongside a State representative in no way establishes a precedent for other non-State actors generally” (Littlechild et al. 2014). After the North American Indigenous People’s Caucus voted to withdraw their engagement from the World Conference because of the lack of meaningful engagement of Indigenous Peoples, Ashe relented, but only slightly, by including two Indigenous advisors as part of the drafting committee. The World Conference went forward. UN Member States negotiated the outcome document based on an Indigenous draft document (the Alta Outcome Document 2013) but without Indigenous influence in the negotiations beyond that of the two advisors (Gilio-Whitaker 2014, Toensig 2014a, Toensig 2014b).

Members of civil society involved in the HIV response face similar challenges when participating in UN and other global fora.<sup>15</sup> As noted in Chapter 1, within the UNAIDS

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<sup>15</sup> Although civil society organizations involved in the HIV response are situated differently from Indigenous Peoples’ organizations. People living with and affected by HIV are not

Programme Coordinating Board (PCB), some UN Member State seated on the PCB have pressed strongly for limits on the kinds of comments and level of influence available to the NGO Delegation to the same board – despite the fact that the NGO Delegation was established by ECOSOC (Resolutions 1994/24 and 1995/2) as non-voting but otherwise full members of the board.

In 2013, governments were successful in restricting certain recommendations from the NGO Delegation. However, they may have reached a limit on what they were able to restrict in December 2013. At the semiannual meeting of the PCB in Geneva, the government representatives of Iran, Egypt, and Zimbabwe worked together to present a challenge to the right of the NGO Delegation to present any recommendations to the other members of the PCB. They argued that issues that could become “decision points” should only be brought forward by UN member states. Other governments expressed their opposition to this position. To break the impasse, the chair sought a legal ruling on the language in the founding declaration of the PCB. UN Legal Counsel reviewed the Declaration and indicated to the PCB his clear sense that the NGO delegation had the authority to participate in everything except voting. This result brought formal clarity to the position of the NGO Delegation and strengthened its standing within the PCB. During the same time period that these challenges have been put forward, the member states of the United Nations have affirmed three times (in 2001, 2006, and 2011) the principle of greater involvement of people living with HIV in decision-making.<sup>16</sup> Subsequently, in July

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defined as a “people” with the rights and recognition, albeit partial recognition, that come with that status.

<sup>16</sup> The conservative bloc within the UNAIDS governing board based its challenge to the rights of the NGO Delegation on the concept of state sovereignty upon which the United Nations system is based. However, this challenge ignores the history of the creation of the

2014, the NGO Delegation proposed a decision point that was approved without discussion or controversy (NGO Delegation 2014a).

Different UN bodies have created mechanisms for involvement of non-governmental or other civil society organizations in their processes. To address the need for a better system that can respond to problems of equitable distribution of public resources, the United Nations Development Programme (UNDP), has recommended the following processes and principles for cooperation between UNDP projects and civil society:

- promoting the principle of stakeholder-decisionmaker equivalence<sup>17</sup>
- developing criteria for fair negotiations
- strengthening the negotiating capacity of developing countries
- developing rules for interactions between state and non-state actors
- creating advisory scientific panels for all major global issues, following the example of the Intergovernmental Panel on Climate Change
- creating **negotiating arenas** for new priority issues (such as the right of access to water for all people) together with **appropriate grievance panels** (such as a world water court)
- creating **demand-driven review and response facilities** to promote flexible implementation of policy regimes, such as a trade and development review council within the World Trade Organization” (from Held 2003, 14-15, emphasis mine).

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NGO Delegation. UN member states, working within ECOSOC, established the resolutions that created UNAIDS and its governing board. Inclusion of NGOs was explicitly noted in both founding resolutions. Rather than an imposition on state sovereignty, NGO participation on the governing board is the creation of member states.

<sup>17</sup> By stakeholder-decisionmaker equivalence, it is meant that those with a stake in projects have an equal voice with those who have formal decision-making power.

In particular, those people and organizations charged with responsibilities for development within human rights frameworks have sought models for the meaningful involvement of affected populations in decision-making. The Special Rapporteur on the human right to safe drinking water and sanitation, Catarina de Albuquerque, focused her October 2014 report to the UN General Assembly on the right to meaningful participation and how this right can be realized, drawing on examples as diverse as anti-poverty commissions in Scotland, participatory budgeting in Italy and Brazil, anti-stigma campaigns against HIV in the US, disability rights in South Korea, and community water boards in Nicaragua (de Albuquerque 2014).

The United Nations Office on Drugs and Crime (UNODC), HIV/AIDS Section, provides an example of rapid change toward inclusion of affected communities in decision-making processes. As recently as 2012, UNODC faced public criticism about the lack of communication with civil society and a related lack of attention to the needs of people who use drugs in their HIV programme. Noting that, “the absence of any systematic form of engagement means that civil society has very limited knowledge of UNODC’s plans, activities and results,” Mat Southwell, a member of the International Network of People who Use Drugs (INPUD) serving as a European NGO Delegate to the UNAIDS governing board at that time, argued, “[i]f UNODC cannot bring itself to embrace and champion the interventions that are central to the response with our community and moreover endorsed by this Board, Commission on Narcotic Drugs and WHO guidance then the growing calls for the lead for the HIV response among people who inject drugs to pass to another Cosponsor will only grow in intensity and legitimacy” (Southwell 2012). He called on “UNAIDS and this Board to help us address the dislocation of civil society from the work of UNODC and for



the endorsement of core strategies by UNODC.” By contrast, only 18 months later in July 2014, the new NGO Delegate from Europe, Brian Texiera, openly praised the Executive Director of UNODC for the relationship that had developed between UNODC and civil society. “We would, in particular, like to emphasize the exemplary work done by UNODC who have, in their HIV response work, set up civil society councils, convened at UNODC’s expense, to advise them in their work. May we recommend that this be adopted as a model for other areas of work, and for other Co-Sponsors [of the Joint UN Programme on HIV and AIDS] to consider replicating this model of engagement with civil society” (Texiera, 2014).

On the other hand, the World Trade Organization leaves no ambiguity about the role of non-governmental organizations in its decision-making processes, indicating that, “[a]s a result of extensive discussions, there is currently a broadly held view that it would not be possible for NGOs to be directly involved in the work of the WTO or its meetings” (World Trade Organization Guidelines for arrangements on relations with Non-Governmental Organizations 1996, VI). The WTO explains that the reason for excluding civil society is two-fold: first, because the WTO is based on treaties among its members and second, because nation-states should be consulting with NGOs at home and are the parties responsible for representing their concerns. Whether or not this happens in practice is not a concern for the WTO because governments are responsible for determining how representation is met.

The WTO position on the engagement of civil society has become a minority position within international fora. Other international and regional institutions with some formalized internal guidance and role for civil society include: the UN Economic and Social Council (ECOSOC) and consultative status NGOs; UNAIDS and the NGO Delegation to the

governing board; the UN Permanent Forum on Indigenous Issues, the World Bank, the International Labour Organization, the African Union and the Centre for Citizens' Participation in the African Union (CCP-AU), the Association of Southeast Asian Nations (ASEAN) and the ASEAN Civil Society Conference/ASEAN Peoples' Forum, and the European Commission among others. While lacking formal mechanisms for civil society involvement, the Union of South American Nations calls on its member states to “promote innovative mechanisms and spaces to encourage the discussion of various issues, ensuring that the proposals submitted by civil society are given adequate consideration and response” (UNASUR Constitutive Treaty 2008).

### ***Summary***

Current calls for inclusion of marginalized affected populations within global fora raise two old questions: who and what is it that call out to be made present? Ideas about which people -- and what interests -- ought to be represented have shifted over time, generally in an expansive direction as more groups have fought for and achieved formal voting rights in legislatures around the world. Earlier ideas about which people are best placed to legitimately make decisions for others are now contested. Instead, groups of people who have been traditionally excluded from decision-making power, whether women, racial minorities, people with disabilities, migrants, or others, have used democratic language about participation, self-governance, and equality, to fight for a place at decision-making tables.

Over time, as decisions that affect peoples' lives are made increasingly outside of state jurisdictions, and as global institutions become central to many health and development initiatives, people affected by these decisions and institutions have pressed

for a recognition of a right to participate in them. These challengers are gaining ground and structures for participation have appeared in multiple UN, global, and regional organizations. Even so, many states – particularly in response to Indigenous Rights organizing – and conservative forces continue to seek to strongly enforce previous paradigms of authority.

These movements by the formerly excluded seek, through participation, not only to influence the decisions that affect them but also to change societal ideas that others -- not them -- are fit to rule. These are liberation struggles for full political adulthood. The struggles are not revolutionary; rather they seek to reform the political system through movement toward equal respect and concern for those who are marginalized.

#### CHAPTER 4 DEMOCRATIC BENEFITS FROM THE INCLUSION OF MARGINALIZED GROUPS

Currently, the great majority of political representation worldwide is based on geographical population groups—so much so that this is frequently assumed to be how representation should be distributed. The underlying assumption is that people who share a geographical location have similar interests and a shared fate, so they should be grouped together for purposes of representation. Why is this? Fundamental to the concept of representation is the belief that the representative should, in some way, share the fate of the represented. Proponents of more inclusive representation processes shine light on the ways in which most representatives do not, in fact, share their fate with their constituents from marginalized groups.

Williams (1998) names inequity in representation for members of historically discriminated-against groups as the failure of liberal representation. She points to overwhelmingly white and male legislatures as inherently problematic symptoms of processes of representation that systematically neglect marginalized groups. Further, Williams (1998, 17) demonstrates that legislators can repeatedly neglect the needs of constituents from racial minority groups without facing any kind of electoral penalty to hold them accountable. These inequities create challenges to realizing justice across the political community and they cause further problems. Those who make decisions for everyone risk being seen as legitimate only by others in dominant groups but as lacking legitimacy in the eyes of members of marginalized groups. Further, it becomes less and less rational for marginalized groups, who persistently find that their needs are left

unaddressed by dominant groups, to participate in processes within which they have no influence.

This chapter focuses specifically on descriptive representation, or processes that require representatives to be members of the group to be represented. Proponents of descriptive representation seek to solve the inequities, questions of legitimacy, and issues of self-government that result from the domination of marginalized groups in other kinds of representation processes. While inclusive representation, the broader focus of this project, is not synonymous with descriptive representation – that is, inclusive representation is focused on the inclusion of representatives of marginalized groups in decision making while descriptive representation insists that those representatives must, themselves, be members of the group – within current inclusive representation processes, marginalized groups frequently select representatives who are group members (as is clear from the membership of the Permanent Forum and UNAIDS NGO Delegation). Indeed, inclusive representation processes offers members of marginalized groups the chance to weigh the benefits of descriptive representation against other considerations in particular cases, for example, exploring the status, networks, expertise, or moral authority that specific candidates might offer.

In political theories of representation and in empirical studies focused on efforts to improve governance for marginalized groups, descriptive representation has been the primary type of representation explored. Works by political theorists including Williams (1995, 1998), Young (1989,1990, 2001), Phillips (1996), Mansbridge (1999), Guinier (1991, 1998), Urbinati (2000) and Sawyer (2000) have rehabilitated the concept of descriptive representation through engaging in difficult normative questions about what

descriptive representation ought to accomplish, who ought to be included, and whether the potential harms might outweigh any possible good. Their writings indicate that they, as Phillips (1996) stated in an article title, offer a “contingent ‘Yes’” to instituting some processes of descriptive representation. Starting with a summary of empirical studies of descriptive representation and then examining the theoretical foundations for descriptive representation, this chapter describes why, despite hesitations, these theorists find descriptive representation to be right for many challenges of our time. The next chapter will explore the obstacles and challenges, identified by many of the same theorists, that such representation poses.

### ***Empirical work on descriptive representation***

Empirical research results indicate that processes that include representatives who come from marginalized groups provide some positive effects for group members, including: increased trust in government, increased political efficacy, and better substantive representation. In the United States, for example, members of minority racial and ethnic groups expressed more trust in government when their representative came from their group (Abney & Hutchinson 1981, Gay 2002). Further, when Maoris in New Zealand and African Americans in the United States were represented by people who came from their group, they expressed a stronger belief in their ability to affect civic affairs (Banducci et al. 2004).

There is some evidence that members of minority groups have their substantive interests better represented when there are descriptive representatives serving. Williams (1998) found that United States Congressional decisions were more attentive to concerns of minorities when minority legislators were present. A series of studies examining the

legislator-constituent relationship for African Americans found that African American legislators are more responsive than other legislators to their African American constituents (Fenno 2003, Gay 2002, Lublin 1997).<sup>18</sup> In Australia, however, examinations of this same question led to different and more qualified results. Nixon (1998) found no differences in levels of responsiveness to minority constituents between minority and non-minority Members of Parliament (MPs), while Zappala (1999) reported the intriguing finding that Australian MPs from minority groups were more responsive to minority constituents – but only when the MPs were on the political left.

This empirical work has been conducted within the context of legislatures, but offers instructive lessons for other forms of political representation. It appears that the theorized connections between trust in government and better substantive representation, in some cases, are largely supported by empirical work. In addition, the increased feelings of political efficacy for marginalized group members when their representatives come from the group indicates, at a minimum, an internal sense of improved status. At the same time, the mixed results regarding responsiveness to constituents highlight the political calculus

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<sup>18</sup> Whether minorities' interests suffer overall from the creation of majority-minority districts is an open question. These districts, designed to increase the likelihood that racial minorities can elect the candidate of their choice and from their racial group, increase the number of representatives who are racial minorities. However, they also shift minority voters out of other jurisdictions where they might be able to influence representatives of dominant groups to attend to minority interests. King (2010) finds a distinct race-class interaction when majority-minority districts are created such that predominantly minority districts are also disproportionately poor districts. He argues, "the practice of excessively packing poor and lower class Blacks into districts diminishes their substantive representation. Once a certain threshold is reached, legislators, Democrats and Republican alike, exhibit the net tendency of becoming more conservative in their ideological temperament as the numbers of poor and lower class Blacks in their districts increase" (838). However, Washington (2012), using different underlying assumptions and focusing on African American votes across class groupings, finds that state delegations from states that increased the number of majority-minority districts in the 1990s showed a slight, albeit non-significant, movement in a liberal direction.

that is ever present for representatives, such as when to press for community wishes, as those wishes are understood by the representative, and when to align oneself with the more dominant voices in one's political party.

***Political theory on the benefits of descriptive representation***

A broad literature that explores the potential benefits of descriptive representation now exists. For the most part, the benefits are seen as accruing to both members of marginalized groups and the political community as a whole. The one exception to this is the potential for increased status for marginalized groups within the larger political community. For those historically dominant, who may lose the ability to easily institute policies of their choice, the increased status for others may not be perceived as beneficial. Drawing together the various works on descriptive representation allows a categorization of the expected benefits as follows:

- Increased quality of deliberation and decisions
- Improved status for marginalized groups
- Stronger legitimacy and accountability for institutions
- Addressing and remedying the lack of recourse within states for marginalized populations

When taken as a whole, these benefits point toward a larger change: that of reduced domination. The democratic legitimacy for amplifying the voice and increasing the influence of subordinated groups is based on the situation of domination into which these groups are otherwise forced. If the theorized benefits of descriptive representation are realized, then previously marginalized groups will experience less domination and greater opportunities to take part in the democratic project of self-governance.



***Increased quality of deliberation and decisions***

The inclusion of members of marginalized groups is theorized to increase the quality of deliberation and decisions through expanding the variety of perspectives considered and ensuring strong and energetic support for the perspectives of marginalized groups (Guinier 1998, Mansbridge 1999, Phillips 1996, Williams 1998, Young 1989, 1990). As expressed by international women's groups in the Beijing Platform for Action in 1995, "Women's equal participation in decision-making is not only a demand for simple justice or democracy but can also be seen as a necessary condition for women's interests to be taken into account" (para. 181). The involvement of members of marginalized groups, whether in legislatures or in decision-making more broadly, brings perspectives that are otherwise missing. Based on historical research on movements by women and African Americans in the U.S. to gain rights to political representation, Williams (1998) argues that members of dominant groups often fail to see experiences, perspectives, and needs of marginalized groups; that these are frequently invisible to them. Similar to the insistence by Mills that the greatest variety of opinions and perspectives were needed for political communities to be able to thrive, Williams argues that the deliberation needed for good decisions is inadequate when the "voice" of members of marginalized groups is absent.

Beyond the increased number of perspectives, which could, by itself, lead to a shallow recitation of various issue positions, inclusion of representatives from marginalized groups is expected to improve decision-making processes through their active engagement and promotion of issues that affect group members. In this vein, Phillips (1995) writes of the "degree of vigorous advocacy that people bring to their own concerns" (69). Similarly, Conover (1988) argues that, "[t]he way we think about social

groups depends enormously on whether we are part of that group. Try as we might, the political sympathy that we feel for other groups is never quite the same as that which these groups feel for themselves or that which we feel for ourselves” (75). This political sympathy and vigorous advocacy for one’s own community creates opportunities for fuller and richer deliberation to occur, which is expected to shape decisions that are better grounded in the life experiences and needs of a broader range of affected people.

Further theoretical support for a positive relationship between descriptive representation and stronger deliberation focuses on the potential for improved communications between constituents and representatives that happens when constituents feel that their representatives can identify with their experiences (Mansbridge 1999) and by the fact that the presence of representatives from marginalized groups forces other decision makers, from dominant groups, to work together with them as peers (Sawer, 2000). Other legislators can no longer make statements about group members behind their backs (or closed doors) (Sawer, 2000). Descriptive representation forces those who argue against women, for example, based on bias or animosity to make those arguments to (at least some) women’s faces. It is not terribly brave or principled to legislate against a group and never be willing to speak your thoughts to their faces or respond to their arguments about your decisions, logic, or evidence. Finally, it is argued that the inclusion of marginalized group representatives challenges unwarranted assumptions that may be held by members of dominant groups. As Young describes, “Such group representation also exposes in public the specificity of the assumptions and experience of the privileged. For unless confronted with different perspectives on social relations and events, different

values and language, most people tend to assert their own perspective as universal" (1989, 262).

***Improved status for marginalized groups***

Other arguments for the presence of marginalized group representatives in decision-making bodies focus on the potential for improved status, and reduced stigma, for the group. Improvements in status are theorized to occur because the presence of members of marginalized groups in decision-making bodies provides a tangible demonstration that they are equals in governing, not simply people for whom others must make decisions.

Mansbridge (1999) writes:

In certain historical conditions, what it means to be a member of a particular social group includes some form of 'second-class citizenship.' Operationally, this is almost always the case when at some point in the polity's history the group has been legally excluded from the vote. In these conditions, the ascriptive character of one's membership in that group carries the historically embedded meaning, 'Persons with these characteristics do not rule,' with the possible implication, 'Persons with these characteristics are not able to (fit to) rule'" (648-9).

She argues further that the anti-stigma effects from descriptive representation should be considered for both those who have been excluded and for members of dominant groups, claiming that the importance of including descriptive representatives from marginalized groups may be even greater for those who have been historically privileged. "It is important that members of a disadvantaged group not be given, in Taylor's words, "a demeaning picture of themselves" (1992, 65)... Yet I consider of even greater importance the effects of social meaning on the perceptions and actions of members of the more advantaged groups. There are sometimes more of them, and they are more powerful. My

aim, in short, is changing the psychology of the 'haves' far more than the psychology of the 'have-nots'" (Mansbridge 1999, 651).

In related work, Young (1989) argues that full participation in decision making improves the social and political status of members of marginalized groups, demonstrating that group members are full members of the political community and participants in resolving community concerns. Indeed, some collectives of marginalized people set this demonstration as a key goal. The Positive Women's Network – USA, a collective of women living with HIV within the US, explicitly links this demonstration with reductions in stigma that members face. They include as part of their mission, "combatting HIV-related stigma and demonstrating the women living with HIV are part of the solution" (Positive Women's Network – USA 2013).

Democratic theorists have long praised the stability of political communities whose members form bonds and interact with one another across multiple social groupings. Theorists argue that political decisions made by these communities -- which Bentley (1908) describes as having "overlapping memberships," Truman (1951) as producing "multiple memberships," and Lipset (1963) as possessing "cross-cutting cleavages" -- are more likely to express moderate solutions to common issues. Political leaders practice moderation because they know, understand, and want to maintain support from individuals from many different social positions. By contrast, a body of political decision-makers, with each leader connected only to his narrowly defined group, faces grave difficulties in making decisions that are acceptable across multiple groups.

What is good for the security of political communities overall is doubly good for the security of members of marginalized groups. When marginalized groups are excluded from

the cross-cutting cleavages within society, their concerns are invisible to the political decision makers. However, as marginalized groups join decision-making bodies, opportunities arise for them to identify commonalities and build cross-cutting relationships with members of more dominant groups.

***Stronger legitimacy and accountability for institutions***

It is argued that institutions enjoy more legitimacy when groups are not seen as perpetually excluded from meaningful involvement in decision making (Mansbridge 1999, Williams 1998, Young 1990, Sawyer 2000). Sawyer (2000) writes that arguments to address underrepresentation are based in part on, “the idea that the legitimacy of political institutions will be undermined if significant sections of the community appear to be locked out of them” (362). Williams (1995, 1998), as described earlier, highlights the challenge to democratic legitimacy when those charged with governing fail repeatedly to look like, or come from, the diversity of groups who are governed. Going beyond an argument based simply on the better aesthetics of inclusive bodies, Williams argues that the legitimacy that follows from inclusion is directly related to the greater trust placed by marginalized communities in representatives that look like them. When representatives come from the group, they are seen as subject to the same laws and decisions, and, perhaps more importantly, subject to the same enforcement, as group members in general. As a result, members of marginalized groups see the decisions that their representatives support as more legitimate than decisions that are made without the support of anyone from the group.

In addition, theorists including Held (2005), Scholte (2011), and Young (2007), promote inclusive representation precisely for its potential to increase accountability of

global institutions and civil society organizations, places where electoral cycles do not exist. Representatives from civil society organizations are credited with increasing the accountability of global organizations by observing global organizations' processes and actions and by creating communication links between decision-makers and grassroots communities at home and, with the advent of social media, around the world. Accountability of global organizations is bolstered when representatives of affected populations are present in the rooms where decisions are made. Civil society representatives not only share information widely about what takes place within global decision-making fora, the fact that they are there, what Philips (1995) calls the "politics of presence," changes the decision-making dynamic. It is a very different process for people in power to make decisions when the people affected by the decisions are with them, looking at them, from within the same room.

Even without formal decision-making power, the presence of these representatives allows the exercise of the "negative power of the people" (Urbinati 2006), providing source material and direct witnesses for monitoring, following up on promises, and challenging decisions or processes deemed anti-democratic or against human rights or other global norms and agreements. Applying Urbinati's concept of the "negative power of the people" to non-legislative arenas, Bray (2011) writes of the "professional organizations (political parties, NGOs, unions, public ombudsmen, think-tanks, etc.) that *monitor, influence, judge and shame formal power-wielders* (and each other) on behalf of, and in the view of, a citizenry of lay people who remain the final court of appeal" (198-199, emphasis mine).

An example of a professional organization serving these functions is AIDSPAN, an NGO in Kenya established as an independent monitoring and reporting organization in the

wake of the development of the Global Fund to Fight AIDS, Tuberculosis and Malaria. AIDSPAN regularly evaluates the Global Fund, such as reporting the extent to which the Global Fund actually turns down applications if the country has not included representatives of people living with the diseases in the country-level decision-making bodies (the Country Coordinating Mechanisms) and the results of Global Fund inspections for proper management of funds (Garmaise 2015, Kinyanjui 2014, Rivers 2010).

***Addressing and remedying the lack of meaningful recourse within states***

Lack of equal protection of rights or concern for dignity by states toward marginalized populations is not only observed when state interests are in direct conflict with those of minority groups. Instead, the relationship between the state and marginalized groups is characterized by low levels of concern. This is the basis of the second democratic argument for inclusion in global governance expressed by marginalized groups. For example, speaking of the movements by Canadian First Nations peoples in the 1970s, Dahl argued “Even in a democratic country such as Canada, all appeals for respect for the unique Indigenous cultures were in vain. Faced with this situation, the Indigenous peoples looked outside their communities and countries for support” (Dahl 2009, 35). Alberto Chirif, Peruvian anthropologist and advocate for the rights of Amazonian Indigenous peoples, describes the “deep democratic roots” of Indigenous societies in Latin America, saying, however, that these societies are “yet not subject to the representational processes on which our society claims to base the principles of democracy” (2006, 15). In a similar vein, Dodson notes the increase in international visibility of Indigenous Peoples and engagement between Indigenous Peoples and international bodies such as the ILO and the World Bank. He compares this to the situation domestically in which “it is still the case that Indigenous

Peoples in their own countries and regions are among the most marginalized and excluded groups” (Dodson 2001, 202-203, section 11). The anthropologist Brysk concurs, explaining that, after the 1960s, “Indigenous peoples themselves reached out to the international system. Indians sought international protection because they were poor and persecuted and because they lacked political access at home. Many Latin American Indians did not identify with their nation-states, and they were often legally defined as second-class citizens” (2000, 10).

People living with HIV describe a similar situation within which they reach out to global institutions seeking assistance to address the lack of concern for their well-being expressed by their states. For example, the new funding model by the Global Fund seeks to shift funding for programs in middle and upper middle income countries to national governments. However, networks by and for groups such as people living with HIV, gay men and other men who have sex with men, people who use drugs, and sex workers are expressing deep concern. AIDSpan, a non-governmental organization set up by civil society to monitor the Global Funding, reported that, in September, 2013, twenty-four organizations in Eastern Europe and Central Asia sent an open letter to the Global Fund, cautioning them about their expectations that governments would quickly scale up their medical coverage for people living with HIV and arguing that “the proposed transition timeline away from Global Fund-supported programmes towards state-funded programmes is too short and could widen the gap of unmet needs in many newly identified middle-income countries” and needs to consider barriers such as “the ability and willingness of governments to fund these programmes in the future” (Zardiashvili 2013). In a letter to AIDSpan, Dasha Ocheret, the Deputy Director for policy and advocacy for the



European Harm Reduction Network wrote, “Advocacy work at the national level and additional resources must be allocated and made available for civil society if the Global Fund expects UMICs [Upper Middle Income Countries] such as Azerbaijan, Belarus, Kazakhstan and others to fully cover harm reduction programmes and ART treatment with domestic funding in the next 12 months,” (Zardiashvili 2013).

A study of the documents put forward by marginalized people seeking the right to participate in decision-making on their own behalf, and by researchers and advocates, reveals further democratic arguments for representation in global governance. The first of these is the lack of meaningful recourse within states when the interests of marginalized groups conflict with state interests. This is especially the case for Indigenous People’s struggles. Kevin Bruyneel (2007) names Indigenous political spaces as a “third space of sovereignty” in which Indigenous people exist within and without the state, but never fully in either (217). Indigenous concerns such as land rights, political representation, and levels of autonomy or self-government reach the core meanings of sovereignty and, thus, are seen as threatening by the states in which they reside. Protections of Indigenous rights often conflict, or are seen to conflict, with profit-generating plans by local land owners, multi-national or local corporations, or the state (Colchester 2005, 18). Young (2007) argues that sovereignty is better understood as non-domination for states and people alike. In Young’s articulation, shared power between marginalized groups and states is possible without a loss of state sovereignty. The challenge, however, is to convince states to agree.

In 2007, inclusion of the term “peoples” to refer to Indigenous Peoples was a major accomplishment in the UNDRIP.<sup>19</sup> States with Indigenous populations have fought against any recognition of Indigenous Peoples as “peoples” in a legal sense as important rights of self-determination are linked with the designation of peoplehood. Article 1.1 of the International Covenant on Civil and Political Rights states, “All peoples have the right of self-determination. By virtue of that right, they freely determine their political status and freely pursue their economic, social, and cultural development. However, UN member states gave with one hand what they took away with the other. States demonstrated their continued resistance to recognizing Indigenous Peoples as holding equal status with other “peoples” through the particular and restricted definition offered within the UNDRIP. The last article of the Declaration, Article 46.1, reads,

Nothing in this Declaration may be interpreted as implying for any State, people, group or person any right to engage in any activity or to perform any act contrary to the Charter of the United Nations or construed as authorizing or encouraging any action which would dismember or impair, totally or in part, the territorial integrity or political unity of sovereign and independent States.

This restriction on the meaning of self-determination serves to dilute its essence entirely.

Because Indigenous Peoples and states have competing interests, the state is frequently unable to serve as the body responsible for protecting the rights of Indigenous Peoples within its borders. “In the context of such claims, therefore, the state ceases to be

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<sup>19</sup> States with Indigenous populations have fought against any recognition of Indigenous Peoples as “peoples” in a legal sense. Important rights of self-determination are linked with the designation of peoplehood. Article 1.1 of the International Covenant on Civil and Political Rights states, “All peoples have the right of self-determination. By virtue of that right, they freely determine their political status and freely pursue their economic, social, and cultural development. States have not wanted to recognize Indigenous Peoples’ claims of self-determination, as demonstrated by the particular and restricted definition offered within the UNDRIP.

the guarantor of rights and is revealed instead to be a bearer of opposing rights” (Beier 2007, 5). In this case, Indigenous Peoples must seek recourse at the global level as “[t]he state, in these circumstances, cannot be the arbiter of claims that unsettle its own foundations and is thus determined by its own logics to become the object of resistance” (Beier 2007, 5). Dalee Sambo Dorough, Director of the Indian Law Resource Center in Alaska, writes, “[Indigenous representatives] have repeatedly and respectfully requested that the United Nations and its Member States uphold their own norms and principles of equality, non-discrimination, and the prohibition of racial discrimination with respect to Indigenous Peoples. However, Nation states have repeatedly ignored our statements and carried on with their attitudes of superiority” (Dorough 2001, 113-114). Indeed, Varese (2006) documents the processes by which, “for over two decades, the Indigenous people of the Americas have carried their struggles and debates to the United Nations arena, demanding a process of democratization of the international body as well as less nationalist positions” (231).

### ***Summary***

The idea that every adult person in a political community ought to have an equal vote with all the others has become fundamental to the definition of democracy. Yet, this formal equality has disappointed proponents of more substantive democracy who seek outcomes that represent perspectives and interests that go beyond the usual elites. It has also disappointed those who anticipated that decision-making bodies that look more like the political communities they represent would have outcomes that demonstrated a stronger influence by the groups that were previously excluded.

The concept of descriptive representation has inspired a great deal of theoretical work, combined with a number of empirical studies of the effects of minority representatives on legislatures and their work. Empirical work supports theoretical arguments that descriptive representation can increase trust in government by members of marginalized groups and may improve substantive outcomes for these groups. However, political considerations still apply for representatives as they determine the best alliances and spaces to place their energy.

Political philosophers anticipate that the participation of descriptive representatives in decision-making processes supports many democratic goals. Greater inclusion of affected communities brings perspectives and information to decision-making bodies that they would otherwise lack, increasing the quality of deliberations. Better deliberations offer the potential for increasing the quality of outcomes. Further, the very presence and participation of members of marginalized groups in decision-making disrupts stereotypes within dominant communities regarding the value of the group. Instead of normalizing dominant group members as the rule makers and marginalized group members as the rule followers, seating members of both groups on an equal basis within decision-making bodies creates a new meme: that members of groups historically excluded from power have a rightful and equal part to play in shaping the collective future. When descriptive representation is established, then institutions of governance may gain a legitimacy they lacked, particularly among marginalized groups who experienced little evidence of concern for their interests previously. In addition, inclusive of representatives from marginalized groups can result in greater democratic accountability by these institutions to the people they are supposed to serve. This is particularly true in global

institutions that have few democratic accountability mechanisms available to them. Finally, including representative of marginalized groups in global bodies, allows these groups a way to seek recourse for the lack of state concern domestically. Marginalized groups may seek global attention in order to pressure their states to follow and attend to their interests and needs. Each of these potential benefits of inclusion, while a democratic good in its own terms, is part of a larger goal: non-domination of marginalized groups by more powerful social actors

Representation of people does not assure that all relevant interests are considered or that substantive outcomes will result. If adopted, the next step is to consider processes to ensure that representation leads to an effective voice. Inclusion is necessary but not sufficient to ensure that people can be heard and can influence the outcomes. We must still ask, once members of marginalized groups are included in the deliberative body, what challenges do they face in gaining adequate attention and responses to their issues?

## CHAPTER 5 OBSTACLES FOR MARGINALIZED GROUP REPRESENTATION IN GLOBAL ORGANIZATIONS

Some of these meetings our international activists attend...can sometimes be lonely and isolating places. Places where we can end up questioning our own abilities, when slowly but surely we can end up feeling our backs are up against the wall, trapped, trying to find a way to push forward our agenda in an environment that has no room or time for the depth of what we are trying to get across in today's incredibly fast paced and highly politicized world.

Sometimes, the terrible burden of responsibility our representatives feel for our community in these fast-moving, process driven, rarely straightforward meetings can eat away at us from deep inside... as we, too, are expected to play the game of process, business meeting etiquette, all the while trying to find out just how to ... get our issues heard - especially the issues that are at the crux of our self-determination (like decriminalization, for example), when there is just no room or time to even begin to unpack such topics around the resulting 'collateral damage' (that's us, dudes, you and me in this crazy war on drugs)...Even that aside, it can be devastating, difficult, lonely, scary.

Eliot Albers, International Network of People Who Use Drugs, 2013

The previous chapters provided democratic arguments for increasing representation of marginalized groups and a foundation for understanding the political processes and strategies that have shaped the struggles for dignity, recognition, and political equality by Indigenous Peoples and people living with and affected by HIV. This chapter focuses on the challenges to creating representative processes for marginalized groups, and to ensuring that those processes are liberatory. To be liberatory, representative processes for marginalized people must generate movement toward political equality, such that space and opportunities are created for marginalized groups to see their issues treated with equal levels attention and respect and to meaningfully influence political decisions that affect them.

As previously described, there are a number of reasons that marginalized people might seek representation in global settings. Marginalized people have, by definition, a fraught relationship with their state and government. Frequently, they have few illusions that they can turn to the state to remedy rights violations and little expectation of equal treatment within political processes. The combination of domestic marginalization and the spread of global human rights language to excluded peoples, communities, and groups, has led many marginalized groups to turn to the global arenas as one site for their struggle for political voice.

The democratic benefits that can accompany increased representation are critical for marginalized groups seeking a full and equal voice in the decisions that concern them. These benefits include: reduced domination by powerful elites (Young 1989, 1990, 2007); opportunities to share information about group interests and express group needs (Urbinati 2000), leading to better decision-making (Young 1990); increased opportunities for different marginalized groups to learn from one another and develop shared goals and strategies (Urbinati 2000); accountability for global organizations (Laclau and Mouffe 2001, Young 1990); greater voice by affected people in the decisions that affect them (Held 2003); broadened social status as rightful participants in a shared political project, rather than as people who need to be governed (Young 1989, Mansbridge 1999); and inclusion by others into perceived communities of shared fate (Urbinati 2000).

While the democratic case for increasing representation of marginalized groups into global and other non-elective venues is substantial, the obstacles to doing so in a meaningful manner are also substantial. There must be processes that could reasonably be put into place within which people from marginalized groups could authorize

representatives to participate on their behalf and hold those representatives accountable, have a noticeable influence on the outcomes of decision-making processes, and experience a positive change in status within the decision-making body and without. Before exploring how such processes have been, and might be, established, the obstacles to a framework of liberatory representation need to be identified. The focus of this chapter, then, is on what could go wrong if frameworks for representation are not skillfully developed.

This chapter focuses specifically on obstacles that could limit or bar movement toward more liberatory outcomes for marginalized groups. These obstacles are identified from the literature by political theorists and writings about representation and voice by Indigenous peoples, people living with HIV, and those from key affected populations that bear the highest burdens of the disease.<sup>20</sup>

To be sure, there are many challenges to the effectiveness of any representative process. When the representative process is structured to be inclusive of marginalized groups, specific obstacles may include: limits on group members' choices of representatives (Mansbridge 1999); promotion of the interests of group elites, leading to further silencing of those more marginalized within the group (Phillips 1996, Young 1990); perceptions by dominant group members that larger social inequities are adequately handled and need no further attention within the decision-making body or outside it

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<sup>20</sup> As related to the HIV epidemic, key populations are generally understood as those who have disproportionately high rates of infection and disproportionately low access to resources, health care, or government concern. Key populations always include gay and bisexual men and other men who have sex with men, sex workers, and people who use drugs. Other marginalized groups may be included depending on the epidemiology of each national epidemic (see the 2011 UN General Assembly Political Declaration on HIV and AIDS, A/RES/65/277, para 29). Broader lists include transgender people, poor people, racial and ethnic minorities, immigrants, prisoners, and women and young people (see, for example, the groups that are included, based on context, throughout the UNAIDS 2011-2015 Strategy, UNAIDS 2010).



(Young 1993, 1996, 2001; Williams 1995; Urbinati 2000). Dominant groups may act as if those representing marginalized groups now carry the sole responsibility for ensuring attention to the needs of those groups (Young 1990) or that the representatives can speak authoritatively only about group issues rather than the totality of issues that the decision-making body must determine (Young 1990). Further challenges include: the material and emotional costs of representation that members of marginalized groups bear when they participate; the lack of trust in governments and institutions by many marginalized groups; and difficulties in organizing that result from the often punitive and controlling legal environments for marginalized groups. This chapter seeks to analyze these obstacles in a systematic way. To the end, the obstacles are grouped into three categories: 1) reinforcement of existing power and status hierarchies; 2) effects of structural violence on the participation of marginalized groups; 3) influence of global power dynamics on the room within which civil society can maneuver.

Each of these concerns is directly relevant to the project for liberatory representation. If including representatives from marginalized groups in decision making processes has the effect of further reducing their status in society, of further marginalizing those who are already subordinated within the group, and of further limiting the extent to which their concerns can be considered in the decisions that affect them, then this representation would constitute the continuation of an oppressive system. A liberatory system of representation requires a satisfactory answer to each of these concerns.

***Reinforcement of existing power and status hierarchies***

Existing hierarchies that mark some people in a political community as more valuable and more deserving of power interact with processes of representation in predictable ways. The hierarchies that exist within marginalized groups can privilege group elites and silence those who are subordinated within the group, a particular concern when it comes to the equal rights of women. Further, external hierarchies within the larger society can replicate themselves within the decision-making body, limiting the influence of representatives from marginalized groups.

***Privileging group elites at the expense of those subordinated within the group***

Foremost among the goals of a project to increase marginalized peoples' representation in global settings is to counter the overrepresentation of dominant social groups – and, through them, their specific interests and concerns – in decision making processes. This is done by ensuring that people who are affected by decisions, but generally excluded from a meaningful voice in their adoption or enactment, are seated, on an equal political basis, at decision-making tables. This democratic impulse can, however, have unintended consequences. Critical concerns are raised about whether, and when, processes for including civil society representatives within global venues simply create further venues for people who are more privileged to increase their voice and participation. Further marginalization for those who are subordinated within the group -- for example, women or LGBT people – can result as elites within larger marginalized group are

appointed as spokespersons for the entire group.<sup>21</sup> Looking specifically at what they label as “self authorized” representation in the global sphere, Warren and Urbinati (2008) note:

In the case of electoral representation, an abstract equality is achieved through the universal franchise. There is no equivalent equality of influence or voice in the nonelectoral domain, where the advantages of education, income, and other unequally distributed resources are more likely to translate into patterns of over- and underrepresentation. The many advantages of self-authorized representation—and they are considerable—may also result in increasingly unequal representation” (405).

Similar concerns are raised about inclusive representation in global bodies even when selection processes exist, so that no one can represent without at least a minimal authorization process.

This is a particularly serious concern for descriptive representation, which, because it is structured as if all group members are similarly placed, can act to “essentialize” members of marginalized groups, through treating group members as if they all have matching views, interests, and experiences, and reinforcing existing hierarchies within groups. Young (1990) highlights the difficulties inherent in one person standing in for others, when there is great diversity among the represented. She draws attention to ways in which selecting representatives based on one similarity within a group can increase access to voices along one dimension while suppressing others and urges attention to who might be left out when others are included, particularly in terms of subgroups. Young uses the example of representatives of racial minority groups, selected because they are part of a particular racial group, who may consciously or unconsciously represent only the interests of male, wealthier, or heterosexual members of the group. Mansbridge (1999)

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<sup>21</sup> This point is made by Kukathas (1992) and used as one of his arguments against any group-based approaches to rectifying past injustices or addressing current ones.

raises a related concern, focused on the symbolic effects that might occur if representatives always come from the most privileged within marginalized groups, is raised by. She writes, "If the women representatives are almost all White and the Black representatives are almost all men, however, the implicit message may be that Black women do not or should not rule. A similar message holds for gay men and lesbian women" (649). As Okin (1999) warns:

When liberal arguments are made for the rights of groups, then, special care must be taken to look at within-group inequalities. It is especially important to consider inequalities between the sexes, since they are likely to be less public, and less easily discernible. Moreover, policies aiming to respond to the needs and claims of cultural minority groups must take seriously the need for adequate representation of less powerful members of such groups (23).

The opportunity for unfair influence across geographic lines is particularly acute in global representation. Held (2003) writes, "to avoid citizens of developed countries being unfairly represented twice in global politics (once through their governments and once through their NGOs) special attention and support needs to be given to enhance the role of NGOs from developing countries" (20). Further, because NGOs from developing countries are frequently supported by governments and donors from wealthier countries, protections to ensure their independence in global governance are necessary. Any process of representation intended to provide marginalized groups a meaningful voice in decisions that affect them must adequately respond to concerns about determining the legitimacy of representatives, assessing the democratic contributions of these representatives, and ensuring that the voices, needs, and perspectives of the most marginalized groups are not overpowered by more privileged members of civil society.

Even within the often times radical and emancipatory politics practiced by Indigenous Peoples and people living with HIV (as described in the next chapter), these inequalities of power and privilege are sites of constant struggle. Indigenous women often face discrimination on the basis of gender, ethnicity, and, frequently, poverty (Roy 2004). In the intersecting dynamics of gender, race, sexual orientation, and poverty, in the early U.S. activist response to the HIV epidemic, women, people of color, and low income people struggled to have a voice in the activist response (Stockdill 2003). Female sex workers continue to lack inclusion in decision-making bodies outside of their own networks (Das and Horten 2014). In 2010, the Global Network of People Living with HIV changed its board membership to include specific seats for key affected populations after determining that regional representatives too often provided inadequate representation for the most marginalized people living with HIV in their regions.

In current Indigenous organizing, older leaders and those without formal education sometimes find entry to decision-making processes closed to them but open to those who are younger and better educated. “Over the last few years, a new generation of Indigenous leaders has arisen, usually younger and with more formal education than previous leaders. This is unequivocally a step forward but it is not without problems. Without these young educated people, the Indigenous communities would not be able to present their case in an efficient way to the surrounding society” (Dahl 2009, 123). These problems are from the attention to one more privileged part of the group, who fit the surrounding norms more closely, and the lack of attention to other voices within the group, those with less formal education but other experiences and bases for understanding.

When communities intentionally work to ensure that all subgroups have their interests addressed, inclusion can still be difficult. For example, a “Common Ground” meeting was held in 2010 to develop shared advocacy messages among gay men, women, young people, transgender people, sex workers, and people who use drugs. The meeting report carried a sense of optimism, “Participants were positive about the ability to carry one another’s messages and noted examples of lesbian communities supporting gay men and women’s groups supporting gay men’s issues.” However, the report went on to document that, “Discussions were also realistic about the difficulties of working in coalition and the fear of many that it would be difficult to uphold this commitment of shared messages once they leave the meeting and are faced with pressures from members of their own constituencies who had not been part of the process” (MSMGF 2010).

Obstacles to a representation that is truly emancipatory, then, include any processes that have the effect of amplifying the voices of the most privileged within marginalized groups and continuing to ignore those who lack such privilege within the group. Those who are subordinated within marginalized groups vary based on the group, but often include women, lesbian, gay, bisexual, and transgender people, racial or ethnic minorities, people with disabilities, people from the Global South, or those who are stigmatized because of a behavior, such as drug use or sex work in the case of the HIV epidemic.

*External inequalities exert influence within the decision-making body*

Probably the most critical concern about descriptive representation focuses on the ways in which external social hierarchies continue to exist within decision-making groups, which can effectively curtail the ability of representatives of marginalized groups to influence decisions (Urbinati 2000, Williams 1995). One purpose of inclusive

representation is to have as much information as possible about the problems to be solved. This information supports a deliberative process, using the combined experience, perspectives, needs, and resources of the group to come to the best possible decisions. The problem, though, is that status differences in larger society impact status within the representative body (Young 2001). In terms of deliberative processes, expressing reasons is fundamental. However, what one accepts as legitimate reasons is contingent on one's power relationship with the person speaking. One person's illustrative example is, to another, nothing more than an anecdote. As Young (2001) contends, there are inherent difficulties for dominant group members in accepting the reasons and evidence of marginalized group members, particularly when these reasons conflict with the interests or perceptions of dominant groups. Status differences in the larger society impede the practice of equality necessary within a representative body. With lower status in the group, representatives of marginalized groups will be less likely to be listened to when they speak or to have proposals adopted and will face significant barriers to developing the relationships needed to gain support for their group's needs (Urbinati 2000).

The risk of tokenism is a constant threat for representatives of marginalized groups. The power relationships that exist outside the group leave members of marginalized groups at a disadvantage in terms of the networks and experiences that are key for building relationships within the group. Further, the effects of stigma mean that members of dominant groups have been taught to consider marginalized group members as less valuable and to ignore or subvert their contributions.

Discussing the negotiations surrounding the United Nations Declaration on the Rights of Indigenous Peoples, Andrew Gray, co-director of International Working Group on Indigenous Affairs, described the tokenism that Indigenous organizations experienced:

Over one hundred Indigenous organisations have now been accredited, although a few have been refused, mainly from Africa and Asia. However they can still obtain access to the meeting by working with NGOs who have consultative status with ECOSOC...Once inside the meeting, Indigenous peoples have had to battle for full speaking rights and to be considered as part of the decisionmaking process.

(quoted in Dahl 2009, 115)

In 2013, the U.S. People Living with HIV Caucus, a network of networks of people living with HIV and individual HIV positive activists, released a policy document entitled: "Parameters for Collaboration with Efforts Seeking to Engage PLHIV Input through the U.S. PLHIV Caucus".<sup>22</sup> This document outlined their process for evaluating whether an invitation to partner was tokenistic or substantive. Their criteria include: involvement by people living with HIV in all levels of the project, from formation through dissemination; broad inclusion of the diversity of communities affected by HIV, with a focus on those most marginalized within the U.S.; and ownership of the results by people living with HIV to use, share, and disseminate.

A misguided hope, or assumption, that responding to inequality can become someone else's problem can prompt decision makers from traditionally powerful groups to support increased representation from marginalized groups (see Young 1990). Similarly, dominant groups may decide that problems of equal representation are solved when a few members of marginalized groups are seated at a decision-making table. However, increasing the voice of marginalized groups in decision-making bodies will fail to create a

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<sup>22</sup> Provided by members of the U.S. PLHIV Caucus, <http://www.hivcaucus.org/contact-the-caucus.html>



liberatory politics if all responsibility for attending to issues of inequality is then placed at their feet.

A slightly more subtle manifestation of tokenism can occur in legislatures when representatives from groups that are marginalized are assumed to only have legitimacy or expertise when they speak about issues specific to their group. Issues of general interest, which by definition would also be of interest to members of marginalized groups, may be seen as falling strictly within the purview of representatives from dominant groups. These representatives, as Young (1990) describes, see themselves as representing universal perspectives in contrast to what they perceive as the particularities of less privileged groups.

### ***Structural violence***

The term, “structural violence” was coined in 1969 by Johan Galtung for events, arising in some way from human endeavors, that have violent effects on groups of people but with no apparent actor causing these effects. In Galtung’s words:

We shall refer to the type of violence where there is an actor that commits the violence as *personal* or *direct*, and to violence where there is no such actor as *structural* or *indirect*. In both cases individuals may be killed or mutilated, hit or hurt in both senses of these words [i.e., physical and psychological], and manipulated by means of stick or carrot strategies. But whereas in the first case these consequences can be traced back to concrete persons as actors, in the second case this is no longer meaningful. There may not be any person who directly harms another in the structure. The violence is built into the structure and shows up as unequal power and consequently as unequal life chances.

(1969, 170-171)

Structural violence is an impediment to meaningful representation for people who are marginalized. Structures and institutions are developed by and for dominant groups. The suffering caused by structural violence is born by marginalized people. If they were not

marginalized, they would have the power, like existing dominant groups, to change structures and institutions. Using the language of structural violence, Farmer (2001) writes about the effects of the global HIV epidemic on poor women and the “differential economy of risk” they face:

Their sickness is a result of structural violence: neither culture nor pure individual will is at fault; rather, historically given (and often economically driven) processes and forces conspire to constrain individual agency. Structural violence is visited upon all those whose social status denies them access to the fruits of scientific and social progress (2001, 79).

Marginalized groups need access to power in order to address the effects of structural violence on their communities. However, structural violence makes participation difficult, with the difficulty increasing the more marginalized one is. Higher rates of poverty among marginalized groups, lack of funding for their organizations, poorer health, and legal frameworks that criminalize marginalized people’s identities and restrict their freedom of movement are among the most basic effects of structural violence on representation.

Poverty continues to limit representation of low-income communities. People with less education, who speak in local dialects rather than the grammar used by national elites, who lack internet access, or who do not own a credit card for checking into a hotel or funds to prepay costs and wait for reimbursement, are frequently unable to participate and bring their voices to decision-making bodies.

Smaller organizations often lack funding or organizational capacity to participate. Individuals have widely differential access to education and resources. Dahl (2009) notes that discussions about weak organizations were a frequent concern for IWGIA:

[I]t became clear that one has to be realistic when it comes to the possibilities of Indigenous peoples’ organisations fighting for their rights without support from abroad. Maintaining an office in town, purchasing

equipment, paying salaries, travelling back and forth between remote communities, taking part in international meetings etc, requires financial resources that are beyond their capacity. Few governments are willing to provide these resources since they are often the targets of these organisations (124).

Laws that criminalize marginalized populations and restrict their mobility present another pernicious manifestation of structural violence. If one risks hostile police attention simply by attempting to organize with similarly situated others, such as gays and lesbians (ILGA 2014),<sup>23</sup> transgender people,<sup>24</sup> sex workers,<sup>25</sup> immigrants,<sup>26</sup> even women in countries that restrict their right to move freely (see, for example, HRW 2008), then creating a network of affected people or a non-governmental organization becomes difficult. Even when these networks and organizations exist, representation from them to global bodies is deeply risky for individuals and the group. If a group of marginalized

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<sup>23</sup> The International Lesbian and Gay Association (ILGA) published, through 2014, an annual report on laws that criminalize and those that recognize same sex relationships. In 2014, they reported that same sex relationships were illegal in at least 78 countries and that homosexuality was punishable by death in at least seven (and possibly eleven) countries. Itaborahy & Zhu (2014) at [http://old.ilga.org/Statehomophobia/ILGA\\_SSHR\\_2014\\_Eng.pdf](http://old.ilga.org/Statehomophobia/ILGA_SSHR_2014_Eng.pdf)

<sup>24</sup> No list exists of countries that protect the rights of transgender people. The closest document is the ILGA 2011 report which provides information on laws for name change after transition and on employment non-discrimination (ILGA 2014).

<sup>25</sup> In most of Latin America, Europe (outside of the countries of the former Soviet Union), Canada and New Zealand, sex work is technically legal, although there are differences in whether it is regulated by the state and whether clients of sex workers can be prosecuted (the “Nordic” model, also adopted in Canada). In most of Africa, the Middle East, Central and Eastern Europe, Asia, and the United States, sex work is illegal and sex workers can be prosecuted. Where sex work is illegal, sex workers are routinely harassed, assaulted and raped, robbed, and arrested by police (WHO 2005).

<sup>26</sup> The U.S. Human Rights Network was formed in 2003 as a coalition of US grassroots organizations seeking to press the U.S. to adopt, in practice, human rights policies. police brutality in the U.S. with U.S. obligations under international law. Their 2014 *Shadow Report Submissions to the United Nations Committee Against Torture* documents multiple forms of police and other State violence against immigrants, as well as against African Africans, LGBT people, Indigenous People, and people who are incarcerated (U.S. Human Rights Network 2014).

people overcomes these obstacles and achieves a voice in decision-making body, the requirements of representation are nearly impossible to meet. Basic representation processes, such as selection of representatives, consultations with communities, reporting back on actions and decisions, and other accountability processes, become dangerous hurdles. For communities that are disproportionately incarcerated, such as Indigenous Peoples and many racial and ethnic minorities and immigrant groups (Hogg 2001, add additional cites), the legal environment creates similar challenges.

Not surprisingly, marginalized groups often lack trust in public institutions. This distrust can be an obstacle to their meaningful participation in representative processes. They may have this distrust for legitimate historical reasons. Public institutions, whether governments, police, health authorities, courts, or schools, have frequently demonstrated a distinct lack of concern for the needs of those without social power (see, for example, Washington 2007). Distrust may be a healthy response when it motivates representatives of marginalized groups to act with caution within decision-making bodies. However, it can work to their disadvantage if it unnecessarily bars relationships that might allow communication and establishment of social networks between representatives of marginalized groups and other representatives. For a system of representation intended to have liberatory outcomes, issues of trust require attention.

Indigenous Peoples' relationships with states and the global system have been shaped by generations of injustice by state actors. In the 1990s, increasing recognition within the UN of Indigenous People's rights as part of the human rights agenda, combined with democratization movements throughout Latin America, the former Soviet Union, and countries in Asia created a challenge for Indigenous organizing strategies. As documented

by Dahl (2009), with these political openings, members of Indigenous organizations faced difficult challenges in determining whether to work in partnership with nation-states and dominant societies where they lived. Tensions arose between the distrust of the nation-state, society, and development agencies and the desire for cooperation with these entities, such that, “to this day, this has remained the foremost point of controversy between Indigenous peoples in international settings” (Dahl 2009, 84-85).

Lack of trust is not the only result of structural violence on marginalized people. An emotional toll is exacted on representatives when they are one of few people in the room embodying the issues being discussed. For marginalized peoples, these issues routinely include questions about whether communities can be trusted to speak for themselves and whether or not harms done to the community qualify as issues of concern for the larger polity. Representatives from marginalized groups report that participation generally involves feelings of great urgency and responsibility that are hard to manage when the other people in the room are not similarly faced with the loss of lives, livelihoods, loved ones, land, culture, or community. The words of INPUD executive director, Eliot Albers, that opened this chapter pay tribute to the representatives who face these emotional challenges.

Further exacerbating the emotional costs of participation for marginalized groups is the reality that, because their struggles for recognition and dignity challenge deeply entrenched social biases and economic interests, battles are never really completely won. Governments or other powerful actors can seemingly always choose to reopen, or simply not fully implement, agreements on issues ranging from fairer distributions of resources to inclusion in leadership bodies. When moving their struggle from a concern that has been

addressed to another concern, marginalized people must be constantly vigilant to ensure that the first issue is not overturned, and, must proceed, likewise, with the second, third, fourth, and subsequent issues.

### ***Global power dynamics***

What happens at global decision-making tables, so long as commitments are well constructed, broadly supported, and implemented, can affect people's lives and can particularly affect the lives of those who are most marginalized. As described previously, a community-driven effort, led by the NGO Delegation to the UNAIDS board, resulted in a dramatic change of course -- from a punitive, law enforcement approach to a human rights-based harm reduction approach -- in policies and programs by the HIV/AIDS Division of UNODC. This example also highlights some of the limits of what civil society representation can achieve. Providing useful insight is Bewley-Taylor's (2012) analysis of the tensions surrounding the international drug control conventions. These tensions appear between UN Member States committed to models of prohibition and punishment, and other Member States, with the rest of the UN system, pushing for greater attention to public health and human rights. Bewley-Taylor notes that UNODC, and particularly the UNODC HIV/AIDS Division, has been moving closer to the human rights approach found through the UN System. However, he also documents the strong pressures by Member States, often led by the U.S., to fight the movement toward harm reduction. The reality on the ground is that some countries, perhaps using technical support and the cover of legitimacy provided by UNODC, have increased their harm reduction programs for people who use drugs. Others, including powerful countries such as Russia and the U.S., have largely refused to institute harm reduction programs, not because such programs are ineffective but because these

programs run counter to the political culture in each country (Malinowska-Sempruch 2008, Williams and Ouellet 2010, Wodak and McLeod 2008).

Within our contemporary iteration of globalization, this example serves as a reminder that it is states that continue to dominate the global system. Although the global sphere is perceived as more supportive of the rights of marginalized peoples than national spheres; the global system is founded upon and structured to maintain the power of states. As a result, state resistance toward marginalized groups at local and national levels continues at global levels. As Dr. William Jonas AM, Aboriginal and Torres Strait Islander Social Justice Commissioner, states:

It is important to note, however, that the World Conference is ultimately a meeting of UN member states. While participation and contributions from non-governmental organizations, National Human Rights Institutions, other UN agencies and affect groups such as Indigenous Peoples is being actively sought, at the end of the day it will be the governments of the world who will negotiate and commit to a program of action at the World Conference (2001, 38).

Chirif (2006) discusses the continuing dominance of the state system within global governance despite the widespread focus on globalization. He explains:

[W]hen one talks of globalization today, two errors are committed. The first is to believe that it is a recent phenomenon...The second consists of considering this as something that democratizes people's access to information and knowledge, when in reality it does none other than reproduce the unequal structures in which they are placed (21).

Drawing attention back to the power of states within existing global systems provides a counter point to much of the literature about civil society's influence within international, as compared with national, spaces. Soguk (2007) demonstrates how international spaces, founded on the power of states, continue to work to maintain the power of states:

Just as the movements of Indigenous peoples continue to pressure states and territoriality into the openness of transversality, resistance to them is most

manifest in sites that states still manage to dominate—formal structures and institutions. Through those institutions at both national and international levels, states still work to capture Indigenous lives while appearing to recognize their political and civilizational qualifications. The most prolific site, paradoxically, is the United Nations where intergovernmental efforts attempt to rein in indigeneity (16).

Soguk describes a number of strategies by states to avoid political recognition of Indigenous peoples, all of which begin by voicing support for Indigenous peoples and then:

1) Denying that any exist within one's own country (China, India); 2) Expressing the view that none of the provisions in the Declaration of the Rights of Indigenous Peoples should be considered legally binding rights (Japan, USA); and 3) Reinforcing state sovereignty, inalienability of national ownership of the land, diversity among citizens, and a concept of the public interest as limits on the practical applications of the declaration (Mexico, Argentina) (18). Using different methods, states continue to shape the response to the HIV epidemic, to determine who will and who will not be recognized in such deeply personal matters as one's gender and those with whom one chooses to form a family, to decide whether state interests in maintaining the status quo will win over scientific evidence about incarceration, drug use, and sex work. It is states that negotiate the language of political declarations and conventions. In the discussions regarding the Sustainable Development Goals (SDGs) that will set targets for states to meet to address global health issues and political, social, and economic inequities, civil society groups actively seek to sway governments toward the positions they feel are right. However, in the end, those who negotiate the language and will be the authors of the Post-2015 SDGs are governments.

Notwithstanding the continuing power of the state and related challenges for marginalized groups to influence global processes, other theorists argue that what is worse than state power and is the loss of state power. For these theorists, the current era is



characterized by, if not the withering away of the state, then its subduction.<sup>27</sup> As Colchester (2005) argues in relation to Indigenous Peoples, “[I]ronically, one of the most acute difficulties facing Indigenous peoples in this era of change comes from the withering away of the state, not its extension” (15). As multinational corporations increase their power, the state has decreased power to regulate business activities within its territory (due in large part to World Trade Organization agreements) and, in many cases, to provide human services (due to previous structural adjustment programs, debt, poor governance practices, and the effects of global financial strain). As a result of weakening states, in this view, Indigenous groups now lack clear pathways for lodging grievances or pressing for participation rights.

For Warren and Jackson (2002), both perspectives have an aspect of truth. While they disagree with Colchester’s assessment that the state is weakening; they do not take on the question of whether the nation-state, historically less willing, is now also less able to provide the protections that are expected from a state. They argue:

The state remains a crucial focus of Indigenous activism because state politics continues to mediate the impact of global political and economic change on local communities. Despite economic globalization, it does not make sense to dismiss the state as irrelevant. Given the way states continue to repress Indigenous communities, such generalizations fail to capture the crosscurrents of change in late capitalism...the state has not withered... (12).

They do go on to conclude that “Indigenous struggles for greater autonomy are enacted within the pressured context of global capitalism, which makes the nexus of state and transnational affairs an important backdrop to the histories of activism...” (13). As

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<sup>27</sup> Subduction is a geologic term that refers to the forceful covering up of one tectonic plate by another. The term is used here to recognize that the state continues to exist with some strength but under tremendous pressure from global trade agreements and multinational business interests. By contrast, Colchester (2005, 15) goes further, arguing that the current era of globalization is leading to the “withering away” of the state.

marginalized groups press for influence in decision-making, determining whether or not state-centric systems are likely to maintain enough power to ensure that any negotiated agreements take meaningful effect will be critical.

Even more complicated, however, is the final concern about global power dynamics. Marginalized groups seeking influence through participation in the global sphere may find that the system of state cooperation is more fragile than it initially appears. There can be an inverse relationship between civil society influence and the perceived legitimacy of global institutions by States. The result is that increasing representation of marginalized groups may cost legitimacy in the global system; thus, destabilizing the very system from which recourse is sought.

In the discussion in Chapter 4, one of the democratic benefits of increasing representation for those who are marginalized was the increased legitimacy that decisions would carry as a result. Indeed, after examining civil society participation in the governance of global health institutions, Abbott and Gartner (2012) conclude, “that direct participation would increase civil society contributions to environmental and other international institutions, especially along the dimensions of legitimacy, deliberation, and effectiveness” (25). However, looking at the structure of the global system, more specificity about this democratic benefit is needed. In fact, the increased legitimacy occurs primarily within the marginalized group and, perhaps, fellow nationals. It does not follow that legitimacy would increase among other groups. For example, increasing the number of African Americans in a U.S. legislature can result in an increased sense among African Americans that their government is attending to their concerns. Within the global system, greater inclusion of Indigenous Peoples or people living with HIV in decision-making would

likely also increase the legitimacy of the global organization within that group. However, marginalized groups do not provide the fuel on which the global system runs. Member states do. The increased legitimacy for those who are marginalized can come at a heavy cost. As Keohane (2002) explains:

If we recognize that powerful states pose the most serious threats to accountability in world politics, we will see that well-meaning efforts to demand “more accountability” from international organizations can be problematic. As I have argued, “more accountable” often means “accountable to NGOs and advocacy networks,” rather than just to governments. Certainly some real benefits could result from making the WTO and the IMF more accountable to a wider range of interests and values. But we should be alert to the prospect that the political result of such a shift would be a reduction of states’ interests in such organizations. If states get less benefit from international institutions, they will be less willing to provide resources and to accept demands on them, through these institutions, for accountability. The ultimate result of such well-meaning moves, therefore, could be a weakening of the accountability, limited as it is, that multilateralism imposes on powerful states (29).

For a theory of liberatory representation, a basic principle must be that the representation, at a minimum, leaves those who are marginalized no worse off than they would have been without this representation. If representatives of marginalized groups gain influence within global institutions, but global institutions lose their influence on states, then marginalized groups are likely to lose out overall. Instead, a reasonable balance will be needed that maintains the tensions of the current consensus system. While maddeningly difficult to find consensus across the different beliefs, and interests, of Member States, the stubborn commitment to negotiations until there is an agreement that every can accept is what maintains the unity and authority of the global system.

***Counter strategies: Responding to global, state, and local challenges***

People belonging to marginalized groups have developed counter strategies to respond to some of the obstacles they face when organizing and working to gain a political voice in decision-making processes. These counter strategies have included efforts to raise consciousness and build a shared political identity, to frame struggles in the language of human rights, to “leapfrog” over national level processes to the international system when national political systems fail them, and to ensure that they are represented in ways that they choose, even when not invited or allowed to speak.

***Consciousness raising and political identity formation***

Identifying problems as group problems, with political solutions, rather than as individual failings is a necessary component of community organizing work. Marginalized groups have taken this practice and used it to both raise political consciousness and develop a shared group identity in order to address shared problems. Following practices in line with Freire’s (1970) concepts of critical pedagogy, both Indigenous Peoples and people living with HIV have formed collective “resistance identities” (Castells 1997). Resistance identities are based in the lived experiences of group members with attention to the structural violence and opportunities for agency that they experience. This framework for identity development opens up an analysis of the power relationships that shape their life conditions and provides a logic of hope that change, through resistance, is possible.

Based on interviews with members of Indigenous groups throughout Latin American, Brysk (2000) documents the development of a common Indian, or Indigenous, identity. In her interviews, common elements identified across different Indigenous Peoples are expressed, such as the shared experiences of colonization and dispossession of

land or finding that outsiders see members of your community as all the same. Brysk's interviews demonstrate the connections made by Indigenous leaders between their local situations and global issues. For example, she quotes pan-Amazon organizer, Evaristo Nugkuag, in 1993, discussing the effects that the 1980 Russell Tribunal had on him, "From international contact, I realized that my problem is politics—not folklore" (2000, 63).

Similarly, in studies of movements organized to respond to the HIV epidemic, Aggleton et al. (2003) document that, "Resistance identities quickly arise in response to stigmatization. All over the world, people with HIV/AIDS, both individually and collectively, have been at the forefront of efforts to challenge the negative social identities ascribed to them. They have been joined in their struggles by individuals and groups (including doctors, politicians, health care workers, teachers and academics) disturbed at the near exclusive portrayal of people with HIV/AIDS in negative terms" (12, see also Parker and Aggleton 2003).

#### *Framing struggles in the language of human rights*

Marginalized groups have learned to use human rights language to describe their circumstances and stake claims to the protections guaranteed within the language of these rights. For example, Brysk describes the way that some indigenous groups have defined local demands according to international standards (2000, 59). In this way, international standards become a source of power that is accessible to those at the margins. In fact, the work of many NGOs has come to involve translating international human rights language and standards into locally relevant language and situations (see, for example, Merry 2006, on how human rights norms against gender violence are translated for local advocacy and education). In the Common Ground meeting, described earlier, held by marginalized

populations affected by HIV, the language that was developed focused on human rights as the centerpiece of the advocacy agenda:

We agree on a human rights framework on all levels. Individually, by recognizing and building on human dignity and meaningful involvement, and also in approaching potential tensions and disagreements. As a movement, by looking at HIV in terms of 'health as a human rights movement' and grounding our language in the human rights entitlements of all human beings. This includes collective action to maintain rights at the heart of the movement and pushing a rights agenda in face of disease specific approaches.  
(MSMGF 2010)

In August 2014, nine respected community-based organizations in the U.S. used this strategy to develop a report to the United Nations Committee on the Elimination of Racial Discrimination titled, "HIV Criminalization, Poverty, and Health care Access – United States' Violations of the International Convention on the Elimination of All Forms of Racial Discrimination" (Int\_CERD\_NGO\_USA\_17737\_E-3). Gathering data from multiple U.S. areas on racial disparities, criminalization, poverty and employment, and health care access, the coalition used the language of human rights and racial equality to systematically document the inadequacy of the U.S. government response to HIV. In their words:

The US government's response continues fail to recognize that high infection rates are due in part to a combination of unjust and uneven policies and laws that enforce racism, stigma, criminalization, and discrimination, thus hindering access to health...The above-listed organizations submit that this disparity – in part due to laws, policies and practices – continues to systemically discriminate against communities of color; increases vulnerability to HIV transmission and to stigma and discrimination following HIV diagnosis; and places people of color living with HIV at undue risk for criminalization and human rights violations.  
These failures also represent a violation of the US' international obligations as a State Party to the International Convention on the Elimination of All Forms of Racial Discrimination (CERD)... (2).

Human rights language, human rights conventions, and the existence of a human rights monitoring body provided a new set of tools for analysis and a new venue for presentation.

Using these tools and this venue, oppressed groups dealing with racism and HIV in the U.S. and their supporters were able to characterize their struggles as matters of international concern and of human rights.

### *“Leapfrogging”*

For decades, marginalized groups have adopted a strategy of organizing at local levels, then leapfrogging the state to advocate at international levels. From there, they have used their local foundations and international support to bring pressure to the national level. This leapfrogging approach is similar to the boomerang approach described by Keck and Sikkink (1998), but with one key difference. In Keck and Sikkink’s study transnational civil society advocacy, people from outside the oppressed group played a critical role. Those directly facing oppression collected information about human rights violations and sent that information to concerned groups outside the country. The outside groups then publicized the information and directed popular and political pressure toward the offending governments. These external concerned helpers might, or might not, share common characteristics with the oppressed group and often did not. By contrast, in the Indigenous Peoples’ and People Living with HIV movements, whether working at the local, international, or national level, all of the activists generally share an identity. In some cases, the same people work at the national and global levels, for example, former ACT UP member and current director of a housing and anti-poverty organization in New York City for people with HIV, Charles King, also serves on the governing board for UNAIDS. In other cases, there are different people working at each level, but all consider themselves part of the same identity group.

*Guerilla representation: Visibility without invitations*

Even when not excluded from participation, marginalized groups have found ways to make themselves present. These strategies include standing silently in visible areas in traditional dress, for Indigenous People, or in identifying clothing, such as the HIV Positive t-shirts worn by members of the Treatment Action Campaign in South Africa. These strategies have a storied history, arising from multiple locations of exclusion. This form of guerilla representation is the art of those who have no other means of influence. Self-representation, in this way, has been practiced in annual days of mourning by Aboriginal Australians in Sydney (beginning in 1938), in the U.S. House of Representatives by the Mississippi Freedom Democratic Party seeking to be seated (in 1965), in the steps of Las Madres de Plaza de Mayo in Buenos Aires (beginning in 1977), and weekly protests at the Japanese Embassy in Seoul by the elderly South Korean women whose WWII slavery as “Comfort Women” for Japanese soldiers continues to be denied by Japan (1992). This insistence on having a presence by people otherwise excluded means that any representations of them that are put forward in decision-making bodies cannot occur in the absence of their own self-representation.

***Summary***

Political theorists anticipate a number of benefits and articulate a number of concerns the greater inclusion of representatives from marginalized groups as a remedy for historical and on-going exclusion. The benefits described are substantial: improved deliberations and better decisions, reductions in stigma and improvements in status for marginalized groups, increased accountability and legitimacy for decision-making bodies, and opportunities to seek recourse for state-level discrimination. At the same time, the



obstacles to a more liberatory politics for the excluded through inclusive representation are considerable. More inclusive representation processes, if not crafted skillfully, can exacerbate existing hierarchies, through replicating larger social inequalities within decision-making bodies and reinforcing relationships of domination and subordination that operate within groups. These challenges highlight the importance for marginalized groups to carefully examine whether, and how much, to press for representation compared with other courses of action to ensure meaningful attention to their needs. This is especially true given the structural violence under which marginalized groups must live and act. This structural violence is characterized by the inactivity of states when it comes to their positive rights (such as social protection and health programs) coupled with state enthusiasm for limiting civil and political rights (as seen by restrictions of freedoms of speech, association, and movement and the criminalization of people for their sexual orientation, gender identity, or HIV status).

Further obstacles to a liberatory politics of global representation come from the power dynamics within the global sphere. Marginalized groups seeking address state-level violations can be frustrated to find that states are in charge of global institutions, and that state sovereignty, not a more cosmopolitan democracy, is their underlying logic. What may be worse are situations where states are not in charge, and trade agreements and multinational corporations create a shadowy yet seemingly impermeable wall for anyone seeking information or attempting to create change. Even when marginalized groups are able to access the decision-making bodies within global institutions, inclusion comes with hard conditions. Although those who have been excluded seek representation precisely to be able to change the existing system, the structure of the system may leave them with one

hand tied behind their back. Because the global system is reliant upon cooperation among states that often disagree on fundamental issues, marginalized groups find they need to attempt to *persuade* states, carefully, to attend to their needs. Activities that press states to go too far beyond their zone of willing compromise threaten to disrupt the consensus-based system and can result in a loss of legitimacy for global institutions. Marginalized groups are caught between their urgency to realize changes in the human conditions of their communities and their need for the willing participation of states to make that happen.

Attention to these obstacles highlights a critical concern for a process of liberatory representation, namely that existing hierarchies of domination and subordination not be reinforced by the very processes intended to bring greater equality. Certainly, this concern should be sobering for proponents of descriptive representation, given the limited resources for all marginalized groups. It calls for a thoughtful examination in each case of when representation, versus activities outside of formal decision-making bodies, is anticipated to offer the best opportunities for meaningful change for the group.

Even so, many of these issues are structural concerns, and, as such, can be addressed to some extent through institutional design. If decision-making bodies are serious about inclusive representation for marginalized groups, then the representation structure can include seats for subgroups within oppressed communities and mechanisms to support their participation. The decision-making body cannot, by itself, end the structural violence experienced by marginalized communities, but it can commit to asking questions and listening carefully to determine the barriers to meaningful engagement and dignified ways to address those barriers. For example, meeting locations can be moved to

accommodate people who have been incarcerated and are unable to move freely; hotels can be pre-paid for people without a reserve of cash or credit; and funds can be offered to support community consultations and translations. Centering the process on the needs of representatives from marginalized communities, rather than simply continuing existing practices, can assist in reducing the effects of structural inequalities. For a liberatory politics of representation, marginalized groups will need careful consideration of the limits of state-centric institutions, such as the United Nations, for meeting their communities' goals. Understanding that powerful state and non-state actors control global fora is daunting and necessary for defining clear goals and strategies for change. Differential advocacy positioning, with strategies coordinated between those who are inside the decision-making body, those who are engaging with states and other government actors, and those who are outside in the hallways, sidewalks, and streets, creates possibilities for change that can push global institutions without pushing them over.

## **CHAPTER 6 THE STRUGGLE FOR THE RIGHT TO MEANINGFUL PARTICIPATION: INDIGENOUS PEOPLES AND PEOPLE LIVING WITH HIV**

### ***Introduction***

In this chapter, I turn to two groups who have seen some success in gaining representation for their communities in global decision-making: Indigenous Peoples and people living with HIV and AIDS. Their stories demonstrate the many ways each group addressed issues of political domination and lack of state concern. The following discussion traces their separate histories as each group organized to develop a sense of identity that transcended local identities, to collaborate across national and regional borders, and achieved formal language calling for their right to participate in decision making that affects them and formal positions within governing bodies of global organizations.

Indigenous Peoples and people living with HIV have pursued separate paths to recognition and inclusion in global decision-making. Their starting points are different: with Indigenous Peoples joining together on the basis of tribal identity and generations of social customs, traditions and geography, as well as marginalization, violence, and trauma by settler and dominant societies; while people living with HIV join together on the basis of a common stigmatized health condition. These two groups are the focus of this project because of their relative successes in convincing the power holders in global institutions that their participation is critical for the legitimacy and success of initiatives that affect them. These initiatives include such wide-ranging areas as land use, economic development, international loans, institutional discrimination, cultural rights, policing, legal reform, education and language policy for Indigenous Peoples and health care systems strengthening, community-based health services, lesbian, gay, bisexual, and

transgender rights, women's rights, family law, gender-based violence, education policy, criminal law, policing, employment policies, prison and immigration policies for people living with HIV. These two groups, while different in history, composition, and culture, share the experiences of marginalization and of finding strength and resources to insist on a space of influence within global governance bodies.

At the same time, the groups are not mutually exclusive. Indigenous Peoples around the world have disproportionate rates of HIV infection as compared to non-Indigenous Populations and experience similar barriers to prevention, treatment, care, and support services as other marginalized people living with HIV (Gracey & King 2009). The International Indigenous Working Group on HIV and AIDS is a global network of Indigenous people living with HIV that seeks to “create an international voice and structure that links Indigenous peoples with their Indigenous leadership, varying levels of governments, AIDS service organizations, cooperatives, and others in a global collective action to lower the disproportionate impact of HIV and AIDS experienced by Indigenous peoples (IIWGHA 2015). Their understanding of the needs of Indigenous people living with and affected by HIV, together with work by Indigenous organizations and networks of Indigenous people living with HIV, such as the International Secretariat of the Indigenous and Afro-Descendants Peoples and HIV/AIDS, Sexuality, and Human Rights in Mexico or the INA—Maori, Indigenous, and South Pacific Islands HIV/AIDS Foundation in Aotearoa (New Zealand), demonstrates how multiple levels of marginalization affect health and wellbeing and how community, identity, and culture can provide resilience and strength. Despite articulating and exemplifying tenets of both movements, Indigenous people living with HIV

have to continually fight for recognition within both the larger Indigenous Peoples' and HIV/AIDS movements.

The following section describes some of the differences between these groups and some of the similarities in the ways in which Indigenous Peoples and people living with HIV found themselves positioned in a world shaped by state-level, regional-level, and global-level governing structures.

### ***Differences between the groups***

Within the Indigenous Peoples movement, identity – claimed or reclaimed – is central. Family generations – grandparents, parents, and children, share the identity. Indigenous identity is understood to be inherent and claimable by group members, even for those who did not previously identify as part of the group (see Eschbach 1993 and Nagel 1996 for examples from the U.S. census data before and after the Red Power Movement). There are local communities of people who all share the identity and work for its continuation. Visible membership in the group, whether through physical traits or open self-identification, can lead to a shared experience of discrimination. This discrimination reaches those who are not visible group members who see the treatment meted out to those who are.

In addition, Indigenous people share a long community history of trauma; with this trauma often hidden or rejected as significant by dominant, non-Indigenous, societies.<sup>28</sup>

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<sup>28</sup> See, for example, the outcry when a Maori academic in New Zealand described the decimation of her people as a genocide or holocaust (Dickson 2012). Yet, whether or not the Maori colonial experience is defined as a holocaust, the reality that intense trauma was inflicted by the British settlers is unquestionable. Pool (2012) reports that the 1890 Maori population was 40% of its 1810 size, with most deaths occurring between 1840 and 1890. Approximately 1% of the New Zealand Maori population was killed by muskets each year,

For Indigenous Peoples, trauma is multi-generational, with new generations of Indigenous Peoples affected not only by on-going racism and discrimination but also by the trauma survived by their parents and grandparents (see, among others, Ball, 2008; Evans-Campbell 2008; Walters et al. 2011). Indigenous Peoples have survived campaigns designed to destroy Indigenous identity, including campaigns of genocide, assimilation, removal from their land, and bans on language and expression as well as the stigma of being portrayed as culturally, linguistically, and developmentally inferior (see, for example, Varese 2010, 50). As a result, Indigenous communities work to reclaim a historic and current culture as a source of power and inspiration and positive self-identity and Indigenous Rights work focuses on poverty and development, political autonomy, land and resource use, migration, and maintaining strong cultural practices and communities (Varese 2010).

By contrast, the People living with HIV movement is a solidarity movement based on a stigmatized health condition. The movement focuses on community and self-empowerment and political agency in the face of fear, judgment, and disgust expressed by wider communities (see Siplon 2002).<sup>29</sup> Sean Strub, one of the leaders in the U.S. movement, has remarked, "This was the first time in history that people with a disease asserted their political voice in decisions that impacted their lives" (McCroy 2014). In

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while another 6% died from infections. It is impossible to differentiate between deaths related to exposure to European diseases that were new to the Maori --which the Europeans could not have easily prevented once they arrived -- and deaths resulting from European activities of colonization: the poverty, crowding, lack of hygienic living conditions, and malnutrition that Maori experienced when they were forced from their lands.

<sup>29</sup> For English-language histories of the PLHIV Self Empowerment Movement in the U.S., see Callen 1990 and Callen and Turner 1997; in France, see Bosia 2005; in South Africa, see Treatment Action Campaign 2010; and in Australia, see Power 2011.

general, identity as people living with HIV coexists with multiple other group identities, with many of these identities also marginalized, such as those based on minority race or ethnicity<sup>30</sup>, sexual orientation, gender, gender identity, or life experience.<sup>31</sup> Often, identify as a person living with HIV is not a central identity except in moments of activism or support or when facing discrimination. Identity as a person living with HIV is rarely shared by family members, except when partners are both living with HIV or when children are born with HIV from a parent who is HIV-positive. As a result, people who contract HIV must generally learn to navigate the related stigma and discrimination without training or support from their families.

With the development of better medications, it is increasingly rare that physical traits make group membership visible. Therefore, to be part of the group, group members largely must self-identify. In the first decade of the epidemic, HIV was more visible to outsiders because of the physical marks created by wasting and opportunistic infections like Kaposi's sarcoma. Since 1996, and the advent of highly active anti-retroviral therapy (HAART), physical identifiers have been dramatically reduced<sup>32</sup>. The exception to this is lipodystrophy, a medication side effect from some medications in which body fat becomes

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<sup>30</sup> Cathy Cohen (1999) demonstrates the barriers to the development of a self or community identity based on a marginalized racial identity (African American in Cohen's work) and a positive HIV status.

<sup>31</sup> Relevant life experiences that may create further marginalization for people living with HIV might include incarceration, drug use or addiction, homelessness, poverty, or sex work.

<sup>32</sup> Sean Strub (2014), longtime activist living with HIV and founder of Poz Magazine, argues that stigma has increased against people living with HIV as physical markers of illness have decreased precisely because it has become more difficult for those who are not HIV-positive, or those who do not know their HIV status, to identify those who are living with HIV.



distributed in unusual ways.<sup>33</sup> Many group members can choose to keep their positive HIV-status a secret; a choice that can protect them from discrimination but also limit the support and healthcare they receive and create intensified internalized stigma (Lee, Kochman, and Sikkema 2002; Physicians for Human Rights 2007; Zhang et al. 2014).

Like Indigenous Peoples, the movement of people living with HIV has been shaped by a history of trauma, violence, grief, and loss. However, this experience is quite different. While Indigenous Peoples have experienced generations of pervasive violence, constantly altering its form and finding new expressions, the HIV epidemic is much more recent. People living with HIV have varied experiences of trauma and grief. In Southern African, the region with the highest HIV prevalence, whole communities experienced multiple losses throughout the 1990s and early 2000s. The survivors continue to deal with the emotional and practical aftermath of an epidemic that killed parents, neighbors, children, friends, and fellow workers in their prime of life (Dow & Essex 2010, Nolen 2007). In other parts of the world, a person's experiences with grief and trauma depend largely on the extent to which that person identifies with other people living with HIV or with one of the groups that is disproportionately affected by the epidemic, such as gay men, transgender women, people who use drugs and their partners, and sex workers. Those who do not access social support with other people living with HIV--whether out of choice or the absence of such support--escape the grief of multiple losses. In return, they experience silence and stigma, and fear about their own health without role models who mirror back

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<sup>33</sup> Lipodystrophy creates noticeable physical changes that are identifiable as illness to those who are not living with HIV; however, recognition that these changes are related to HIV infection is not widespread. As a result, people with lipodystrophy may be stigmatized or discriminated against based on appearance but without linking the physical changes to HIV specifically.

to them their worth and value (Lee et al. 2002, Limin et al. 2009). In countries where the epidemic has decimated gay communities, the trauma reaches back three decades for many survivors. These survivors may be HIV-positive or HIV-negative, men or women, LGBT or heterosexual. They developed resilience but also express feelings of unresolved and complicated grief and emotional distress (Sikkema et al. 2000; Mallinson 1999). In those same countries, women and heterosexual men living with HIV often report telling no one about their HIV diagnosis and frequently report symptoms of depression, isolation, and internalized stigma (Lee et al. 2002; Makin et al. 2008; Aljasseem et al. 2014). Experiences of trauma for people living with HIV frequently pre-date their diagnoses and continue post-diagnosis (Kalichman 2004; Ollie et al. 2005; Matchinger et al. 2012)<sup>34</sup>.

### ***Similarities across the groups***

Beyond the connections forged by those who are both Indigenous and living with HIV, the ways in which Indigenous Peoples and people living with HIV have found themselves situated in the contemporary world have created some common experiences as each group struggles for recognition and inclusion. Each group has found it necessary to forge a shared identity that connects members across a great number of different other identities and allows the framing of a common struggle. A sense of inherently shared

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<sup>34</sup> Meta analysis performed by Matchinger et al. (2012) showed that women living with HIV in the U.S. have an estimated rate of recent post traumatic stress disorder of 30% and lifetime sexual abuse of 61%, both are more than five times the rate in non-HIV-positive women. They also had twice the rate of intimate partner violence (55% compared to 24.8%) and 58% experienced physical or sexual abuse as children, compared to 31.9% of non-HIV-positive women. Research by Kalichman et al. (2004) demonstrated that gay men who were survivors of childhood sexual abuse were more likely to be living with HIV and to experience violence in their intimate relationships. Ollie et al. (2005) have similar findings of high levels of trauma and post-traumatic stress disorder among newly diagnosed people with HIV in South Africa, and particularly highlight the role of intimate partner violence and rape as preceding traumas for women who are diagnosed with HIV.

identity existed for neither group initially. Most Indigenous Peoples have identified themselves by the specific nation, band, group, or name they give themselves rather than as part of one global community (Cornell 1990, Allen 2002). Further, colonized peoples faced government policies designed to forcefully assimilate them into the society of the colonizers and to divide them from other Indigenous peoples within the same territory (Sylvain 2002, Armitage 1995, Nagel 1996). As Dean and Levi (2003) point out, “the category *Indigenous* is an artifact of colonial encounter” (5, see also Carneiro da Cunha & Almeida 2000).

The common thread linking people with HIV into one group is no more than infection with the same virus. However, what might have been a tenuous connection was fortified by the health implications, social stigma, and legal discrimination that attached to that viral infection. As Schneider (2002), in her research on community and governmental responses to HIV, explains:

Until the mid-1990’s, when “HAART” — highly active (triple) anti- retroviral therapy — became widely available in industrialised societies, AIDS was as much a death sentence for a white middle class gay man in New York or Cape Town as for a black working class woman in Kampala or Johannesburg. This unusual commonality of experience, at both the individual and the community level, between North and South, straight and gay, white and black, has facilitated bonds and forms of action across numerous of the classic social divides (157).

Identity in both cases was, to a great extent, initially forced by marginalization and repression and then taken on as a positive characteristic around which to develop shared bonds and to mobilize for change. For a global movement to emerge, a political consciousness of a shared identity based on a set of shared experiences and values had to be developed. Indeed, both groups share a conscious understanding that combining within

and across state boundaries could increase political power and wellbeing for the whole group.

A further shared challenge for both people living with HIV and Indigenous Peoples is internalized stigma and, for Indigenous Peoples, internalized colonization.<sup>35</sup> Organizing on the basis of a stigmatized identity is extremely challenging, especially when those who share the identity have the choice to hide it. The creation of a supportive movement that empowers group members and creates solidarity thus becomes essential to the political organizing processes.

In addition, each group exists across state boundaries and has been required to find methods of organizing that are not reliant on a shared geographical location. Indigenous Peoples and people living with HIV are found in every country of the world with connections that flow across state borders (Varese, 2010, 228). Within each group, a sense of common identity may be stronger across these borders than with others who share national citizenship. While the conditions of life for members of both groups are largely shaped by the state within which they live, or within which their territory is confined, the adoption of a political identity as Indigenous Peoples and as people living with HIV creates a sense of membership in a much larger community of people with a shared fate. Central to the creation of identities is the creation of what Manuel Castells (1997) has labeled “resistance identities.” These contrast with the “legitimizing identities” that are “introduced by the dominant institutions of society to extend and rationalize their domination vis-à-vis social actors. Resistance identities, on the other hand, are those generated by those actors

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<sup>35</sup> For more on internalized colonialism, Varese’s (2010, 51) discussion of the “internalized colonizer’s discourse,” provides useful insights into internalized colonialism and Indigenous Peoples.

that are in positions/conditions devalued and/or stigmatized by the logic of domination” (Aggleton et al. 2003, 11-12).

A final commonality is found in the process of political organizing. For both groups, empowerment and mobilization have been largely self-directed and conducted with a noticeable lack of support from likely political allies. Describing Indigenous Peoples’ organizing in Latin America, for example, Varese writes:

the new Indigenous movement experienced an ambiguous response from its presumed allies...A mixture of indifference, plain ignorance, misunderstanding and even antagonism accompanied the emergence of these organizations. From the perspective of the organized Left and populist parties...the small, fragmented, local and radical ethnic organizations were perceived as divisive, lacking the correct class analysis and, at best, as dangerous and disruptive” (2010, 224).

For people living with HIV, given the strong relationship between HIV infection and structural inequalities, natural political allies would be expected to be LGBT communities, feminist and feminist health organizations, and racial and ethnic minorities. However, despite the fact that movements of people living with HIV draw upon practices and activists from the U.S. civil rights movement, South African anti-apartheid struggle, women’s movements, and gay liberation movements (Karim & Karim 2000, Robins 2004, Senterfitt 2014), support from these different groups overall has been unreliable (Androite 1999, Cohen 1999, Duberman 2014).

This lack of political support can best be explained by Cohen’s (1999) framework of marginalization. Seeking to explain the unwillingness by African American leaders to engage in HIV advocacy in the 1980s and 1990s, despite sharply climbing infection and death rates within African American communities, Cohen posited that secondary marginalization, such as that experienced by African Americans, women, or LGBT people–

and those at the intersections of these groups -- who were also living with HIV is associated with lack of concern from group elites. In Cohen's interpretation, those with more political or social capital are reluctant to using their resources to assist those marginalized within the group – and this is particularly so when dominant groups in the larger society define these minorities-within-minorities as deviant (344).<sup>36</sup> The result is often predictable: instead of joining together, those with the most status and power in the minority group seek to distance themselves and the group from the negative stereotypes inflicted on those further marginalized within the group.

When discussing the common experiences of Indigenous Peoples and people living with HIV, it is critical to recognize that these are not mutually exclusive groups. Like other groups navigating poverty, marginalization, disruptions in living conditions, political and sexual violence, forced migrations, economic immigration, and lesser access to health services, Indigenous Peoples are disproportionately vulnerable to HIV infection. The discussion later in this chapter of the International Indigenous Working Group on HIV and AIDS (IIWGHA) demonstrates some of the ways that an Indigenous response to HIV has developed across borders, similar to the Indigenous Peoples' movements and movements of people living with HIV overall. Further, Indigenous HIV service organizations and networks of Indigenous people living with HIV can be found in a number of countries and regions, including the Canadian Aboriginal HIV/AIDS Network, the National Native American HIV/AIDS Prevention Center (United States), INA – Maori, Indigenous, and South Pacific Islands HIV/AIDS Foundation) and Te Roopu Tautoko Trust in Aotearoa (New

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<sup>36</sup> Cohen (1999) demonstrates the same lack of support by those with more political power in the African American community toward welfare programs and the needs of poor single mothers (see pp. 343-344).

Zealand), ANA – Anwernekenhe National Aboriginal and Torres Strait Islander HIV/AIDS Alliance (Australia), International Secretariat of the Indigenous and Afro-Descendants Peoples and HIV/AIDS, Sexuality and Human Rights (Mexico), and Association for Research, Development and Global Education (IDEI) (Guatemala). These organizations seek to bridge the intersecting marginalizations people experience as Indigenous Peoples and as people living with and affected by HIV.<sup>37</sup>

### ***Indigenous Peoples and the Struggle for Representation***

Perhaps the most succinct definition of Indigenous Peoples is a recent description used by the director of the INA (Maori, Indigenous & South Pacific) HIV/AIDS Foundation, Marama Pala, as “people who have a generational attachment to the land but have no political power over that land.”<sup>38</sup> As the first United Nations study of discrimination against Indigenous people found, definitions for Indigenous, aboriginal, native, and first nations people are complicated and vary widely (UN Doc. E/CN.4/Sub.2/1986/7/Add.4). The study report, labeled the “Study on the Problem of Discrimination against Indigenous Population” (hereafter, the Cobo Report) by United Nations Special Rapporteur José A. Martínez Cobo, provided a definition from by the World Council of Indigenous Peoples (UN Doc. E/CN.4/Sub.2/1982/2/Add.6.para 11):

[I]ndigenous peoples are such populations as we are, who from old-age time have inhabited the lands where we live, who are aware of having a character of our own, with social traditions and means of expression that are linked to the country inherited from our ancestors, with a language of our own, and having certain essential and unique characteristics which confer upon us the

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<sup>37</sup> List of organizations provided by Trevor Stratton, Coordinator, International Indigenous Working Group on HIV and AIDS (IIWGHA), 22 September 2014.

<sup>38</sup> Communication from Marama Pala on the “Indigenous Position” to the NGO Delegation to the UNADIDS Programme Coordinating Board, 24 February 2014.

strong conviction of belonging to a people, who have an identity in ourselves and should thus be regarded by others.

In Chapter Five of the Cobo Report, five broad categories in general use by Indigenous Peoples and states when defining membership were examined: ancestry, culture, language, and group consciousness (UN Doc. E/CN.4/Sub.2/1982/2/Add.6). Ultimately, the Cobo report put forward the following, widely cited, definition of Indigenous Peoples (UN Doc. E./CN.4/Sub.2/1986/7/Add. 4.para 379):

Indigenous communities, peoples and nations are those which, having a historical continuity with pre-invasion and pre-colonial societies that developed on their territories, consider themselves distinct from other sectors of the societies now prevailing on those territories, or parts of them. They form at present non-dominant sectors of society and are determined to preserve, develop and transmit to future generations their ancestral territories, and their ethnic identity, as the basis of their continued existence as peoples, in accordance with their own cultural patterns, social institutions and legal system.

Of the 41 countries described in the Cobo Report, only Costa Rica included provisions formally allowing people who are of Indigenous descent to reclaim that identity even if they had sought to distance themselves previously. The Costa Rican government commented in the report that, “An Indigenous person never loses his status in his heart of hearts” (1982, 66). The Costa Rican government recognized that one effect of persistent stigma would be to seek to escape from association with the group and that, contrary to expectations in other countries, this is not a sign of progress but rather a signal of discrimination. Comments from the Costa Rican government included in the Cobo report stated: and

[W]hen a person who has considered himself to be Indigenous subjectively loses his Indigenous status, as in the case of some students or [persons engaged] in entrepreneurial activities who do not wish to feel inferior, because of a wrong understanding of the term Indigenous in that



environment. This change is not always final, because there are cases of 'Indigenous groups which have become acculturated but who, on becoming aware of the value of their own origins, demand to be considered as Indigenous groups, under the rights established in the existing laws, even though previously they preferred to be considered 'non-Indigenous.'

(Cobo 1982, 66-67, emphasis in the original)

Two decades after the Cobo Report, the United Nations appointed another Special Rapporteur, Miguel Alfonso Martínez, to conduct a further evaluation of the situation for Indigenous Peoples. The resulting report was published in 1999 as the "Study on Treaties, Agreements and Other Constructive Arrangements Between States and Indigenous Populations" (hereafter, the Martínez Report, UN Doc. E/CN.4/Sub.2/1999/20). The Martínez Report underscored the findings of the Cobo Report on the inequalities faced by Indigenous Peoples worldwide. Dr. William Jonas AM, Aboriginal and Torres Strait Islander Social Justice Commissioner, summarized this report as demonstrating, first, that "almost without distinction, Indigenous Peoples across the globe are marginalised and severely disadvantaged in the nations where they live" and, second, that "not much of substance has changed for Indigenous Peoples since [the Cobo Report]" (Jonas 2001, 37). Indeed, in his introduction, Martínez writes of Indigenous peoples, "It is the precarious nature of their existence almost everywhere that is today provoking - as it did when Martínez Cobo's study was commissioned and completed - growing concern in the international community" (Martínez Report, E/CN.4/Sub.2/1999/20E/CN.4/Sub.2/1999/20, para 14).

The global movement for Indigenous rights arose from the combination of persistent discrimination and mistreatment – as documented in these UN reports and understood within the daily experience of Indigenous Peoples -- and a connection to a sense of human and collective dignity and a valuable cultural heritage. The movement is focused on the struggle "for principled change in the status and conditions of Indians as a

distinct cultural group” and includes “Indian organizations, non-Indigenous advocacy groups, and some individuals...who mobilize primarily to improve the position, autonomy, and participation of Indians in their societies and the international system” (Brysk 2000 69). While multiple groups, including many non-Indigenous organizations and individuals, participate in the Indigenous rights movement, leadership and advocacy by Indigenous people for Indigenous people are the focus of the following sections.

*Brief history of the movement*<sup>39</sup>

Building on a history of resistance already 400 years old, the modern movements started in the 1950s, when Indigenous Peoples began organizing councils, working groups, and federations across different Indigenous nations with a focus on creating a shared national or regional voice. This organizing was conducted within a landscape shaped by loss of sovereignty and territory, discrimination by dominant ethnic groups, and the threat of annihilation of lives, communities, and cultures.<sup>40</sup> This organizing adopted the language of human, civil, and political rights and engaged in protest movements that mirrored strategies used by African Americans, women, and other liberation and anti-colonial movements.<sup>41</sup>

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<sup>39</sup> Unless otherwise noted, the history of Indigenous Peoples movement for recognition and representation comes from the timelines compiled by Brysk 2000, Beier 2007, Soguk 2007, Dahl 2009, and Varese 2010.

<sup>40</sup> The threat of physical annihilation refers not to symbolic annihilation and not only to slow deaths from poverty and land dispossession, but also to the massacres and genocides in the 1950s and after, including in Guatemala in the 1950s and 1980s, and the 1968 Tlatelolco student massacre in Mexico.

<sup>41</sup> Key differences existed in the desired outcomes, however, between Indigenous rights movements and civil rights movements by racial minorities and women on one hand and anti-colonial liberation movements on the other. Indigenous rights movements sought recognition of their sovereignty and fulfillment of treaty obligations where treaty relationships existed. Rather than autonomy, civil rights movements sought full equality

From 1956 to 1968, Indigenous Peoples in the north formed the Sámi Council in Norway, the Alaska Federation of Natives in the U.S., and the National Indian Brotherhood in Canada. In 1964, the first Latin American Indian Rights organization, the Shuar Federation, formed in Ecuador, followed, in 1967, by the creation by the Amazonian Amuesha people of Peru of the Amuesha Federation.

From the 1970s through the early 1990s, increased organizing occurred throughout the United States (the American Indian Movement or AIM), Colombia, Peru, Canada (Inuit Tapirissat), Asia-Pacific, Russia (Russian Association of Indigenous Peoples of the North or RAIPON), the Arctic (Arctic Council), Africa, and Brazil. In the 1970s, there were increased actions by Indigenous Peoples to protect their lands and claim rights, including the occupation of Alcatraz Island in the U.S. from 1969 to 1971, the James Bay conflict in Canada from 1971 to 1973, the Chinantec anti-dam movement in Oaxaca in 1973, the confrontation between AIM and the U.S. federal government at Wounded Knee in 1973 and Pine Ridge in 1975, and the Alta conflict from 1979 to 1981 in Norway in which the Sámi successfully protested against a hydropower development project expected to damage reindeer herds. North American Indigenous Peoples in the 1970s took their struggle to the United Nations in an unsuccessful attempt to gain recognition of their right to self-governance, while Canadian (1974) and Maori (1975) Indigenous People marched on their respective parliaments (Canada and Aotearoa/New Zealand) to demand attention to their

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within the existing political structure. Like Indigenous Peoples, anti-colonial liberation movements sought sovereignty; however, the form of sovereignty available to them – and for which they fought – was a return to self-rule and removal of the colonial power from governance. As a result, after the civil rights movements and struggles against colonialism were successful, the people in those movements could expect the existing state to look out for their interests domestically and represent their interests internationally. An expectation that Indigenous Peoples have never been able to hold given the tension between their sovereignty claims and those of the states within which they reside.

concerns. Legal protections were won for individual and community land ownership for people of the Amazon in Peru in 1974. In 1986, the Miskito, Sumo, Rama, and Nicaraguan Creoles and the Sandinista government established an agreement on autonomy for the Atlantic Coast region of Nicaragua after armed struggle that lasted from 1981-1986. In Ecuador, Indigenous movements joined together and demonstrated their political power, in 1990, through successfully pressing the government to respond to a list of Indigenous demands and, in 1997, removing the president for corruption. In the Chiapas state of Mexico, the Zapatista movement gained worldwide attention on January 1, 1994 – the day that the North American Free Trade Agreement (NAFTA) went into effect -- when organized Indigenous people, naming themselves Zapatistas, took control of 6 cities in Chiapas. The Zapatistas brought attention to the Mexican government's neglect of Indigenous and rural people's needs, protesting the revocation of land reform and the adoption of neoliberal trade policies. Ultimately, the Zapatistas retreated back into the jungle areas and established highly effective processes for global communication, political autonomy over local matters, and a space for organizing for Indigenous people in Mexico (Stahler-Sholk 2007). In Bolivia in 2003, the Aymara and Quechua people were similarly successful in having the president, a proponent of neoliberal policies, removed. In January of 2006, the first Indigenous president of Bolivia, Evo Morales, was inaugurated.

However, history has not moved uniformly in the direction of increased recognition of Indigenous Peoples and rights. Setbacks to Indigenous rights were seen in Guatemala where a national referendum to support Indigenous rights was defeated (Warren and Jackson 2002) and in Mexico with the repeal of Article 27 which had guaranteed collective land ownership rights since the Mexican Revolution. Further, in 1997, Mexican President

Fox replaced the the National Institute of Indigenous Affairs with a council with less power, which he named the National Council for Indigenous Peoples' Development, and, in 2001, he oversaw the passage of an anti-discrimination act which the Zapatistas had struggled for initially but which had its land ownership provisions so deeply diluted by the time it was passed that the Zapatistas argued against its adoption.

Global and regional organizing also increased in the decades from the 1970s through the 1990s. At the regional level, this included the convening of an Arctic Peoples' Conference in Denmark in 1973, the American Indian Movement's founding of the International Indian Treaty Council (IITC) in 1974, and in 1984, the establishment in South America of the regional organization, *Consejo Indio de Sud America* (CISA) and regional coordinating bodies from nine countries for joint advocacy and solidarity (named the the Coordinadora de las Organizaciones Indigenas de la Cuence Amazonica, or COICA), and the Cordillera Peoples' Alliance which included twenty-seven Asian Indigenous Peoples' organizations. In 1989, in Brazil, 48 regional groups comprising 140 separate Indigenous Peoples (estimated by Brysk 2000 to represent 180,000 people) created COIAB, the Coordinating Indigenous Organization of the Amazon Basin. Later, in 1992, CAPOIB was founded in Brazil, representing 101 Indigenous peoples. Beginning formally in the 1990s, Indigenous women organized meetings and conferences for solidarity and attention for their needs at the intersection of women's issues and Indigenous issues. Latin American Indigenous women organized the Latin American Indigenous Women's Conferences held in Peru in 1992 and Bolivia in 1994.

Globally, an International Conference of Indigenous Peoples, with participation from Indigenous Peoples from eighteen countries, was held in British Colombia, Canada in 1975.

At this meeting, the World Council for Indigenous Peoples was established, with a governing structure that ensured representation for five regions: North America, Central America, South America, Australia/New Zealand and the Arctic (Inuit and Sámi). The World Council for Indigenous Peoples met every three years for two decades, dissolving in the mid-1990s. In addition, two International Conferences of Indigenous Women were organized by Indigenous women in the 1990s. The first meeting was in Norway in 1990; the second held in Aotearoa (the Indigenous name for New Zealand) in 1993. In 1992, Indigenous Peoples united in an anti-quincentenary campaign, protesting the celebrations of European conquest of the Americas and promoting decolonization and an antiglobalization vision. In that same year, Rigoberta Menchú Tum became the first and only person to date to be awarded the Nobel Peace Prize for advocacy for Indigenous rights. Indigenous women from across the world coordinated for the Fourth World Conference on Women, held in Beijing in 1995, to make a strong call for systemic change in the world economic order and to insist, successfully, on the inclusion of Indigenous women throughout the outcome document (Beijing Declaration of Indigenous Women 1995; Report of the Fourth World Conference on Women 1995). Organizing and advocacy by Indigenous Peoples resulted in a resolution by the UN General Assembly naming the years 1995 to 2004 as the International Decade of the World's Indigenous Peoples (UN Res. 48/163), with the stated goals of creating partnerships between Indigenous Peoples, UN organizations, and states to focus on poverty and development, the environment, and human rights of Indigenous Peoples.

In the last two decades, the current landscape of global Indigenous organizing has developed, particularly shaped by the establishment of the United Nations Permanent

Forum on Indigenous Issues (2000) and the adoption of the United Nations Declaration on the Rights of Indigenous People (2007). Recognizing that the goals for the International Decade of the World's Indigenous People's were not met, a Second International Decade of the World's Indigenous Peoples (2005-2014) was agreed by the UN General Assembly. The Second International Decade was given the theme, "Partnership for Action and Dignity," and the goal of implementing the UN Declaration of the Rights of Indigenous Peoples (UN Resolution 59/174). The Global Indigenous Women's Caucus was established in 2001 and Member States of the United Nations agreed to hold a World Conference of Indigenous Peoples in 2014.

*Involvement in International Institutions: the United Nations*

Indigenous Peoples from different parts of the world have consistently identified themselves as sovereign nations and sought participation as such with the other nations of the world. However, their initial attempts to be included in global decision-making, dating back to the 1923 petition for recognition carried by the Chief of the Cayuga Nation to the League of Nations, were ignored or rebuffed (Telles 2007). The timeline of the relationship between the UN and Indigenous Peoples shows increasing effectiveness at the global level of Indigenous organizing, but within substantial constraints.

Before 1970, almost no meaningful support was expressed for Indigenous issues.<sup>42</sup> Starting in the 1970s, violations against Indigenous peoples started to be included among other concerns relating to racism and discrimination. After further pressure by Indigenous peoples and activists, both Indigenous and non-Indigenous, the first specific attention to

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<sup>42</sup> One notable exception was the proposal by Bolivia in 1948 for a UN sub-commission to address the inequalities experienced by Indigenous peoples in the Americas (see Charters and Stavenhagen 2009). While receiving some support, the proposal failed to be adopted.

Indigenous peoples appears with the appointment of the Special Rapporteur, Martinez Cobo, and his report, presented in 1982.

From that time to the present, Indigenous Peoples have successfully pushed for institutionalized processes that define and protect their rights, in particular, to ensure their right to meaningful participation in all efforts related to their land and resources, and social, political, economic and cultural wellbeing. The Permanent Forum for Indigenous Issues, established in 2000, is one result of this activism. Other results with lasting significance include: the adoption of ILO Convention 169, stating that Indigenous Peoples have the right to actively participate in decision-making that affects them, in 1991; the establishment of the Special Rapporteur on the Rights of Indigenous Peoples in 2001; the Expert Mechanism on the Rights of Indigenous Peoples in 2007; and the adoption of the UN Declaration on the Rights of Indigenous Peoples in 2008.

Nevertheless, Indigenous Peoples find the struggle for representation continues, even within the UN system. Indeed, in 2014, during preparations for the UN General Assembly high-level plenary meeting, named the World Conference on Indigenous Peoples, Indigenous Peoples launched multiple efforts to press for their meaningful involvement in the meeting named for them.<sup>43</sup> A World Conference of Indigenous Women was held in 2013 in Lima, Peru, with a focus on strategizing on shared principles to press for in the World Conference of Indigenous Peoples, Beijing +20 and post-2015 sustainable development goals (SDGs). Another preparatory meeting was held, attended by 600 Indigenous leaders

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<sup>43</sup> This controversy is summarized in the previous chapter as an example of the obstacles to liberatory representation created by global power dynamics. It is described in further detail here to demonstrate the understandings held by Indigenous Peoples of their rights to participation and to provide examples of the ways in which human rights language is used to express these understandings.



from around the world, including members of the Global Indigenous Youth Caucus and the Global Indigenous Women's Caucus, in Alta, Norway, in June 2013. The Alta outcome document formed the basis for deliberations by Member States at the World Conference on Indigenous Peoples.

By January 2014, disappointment had set in. Despite agreements to the contrary in 2012, Indigenous Peoples saw commitment to their meaningful participation in the World Conference decline. In January 2014, noting the lack of Indigenous leadership in the meeting preparations, the three UN mechanisms (the Permanent Forum, the Special Rapporteur, and the Expert Mechanism) sent a joint letter to the President of the UN General Assembly calling for the appointment of an Indigenous leader, as agreed two years earlier, to co-lead efforts to organize the conference.<sup>44</sup>

Instead of responding, the President of the General Assembly released an Aide-Memoire, in February, describing separate consultation processes for Member States and for Indigenous Peoples to determine whether representatives of Indigenous Peoples should be invited to co-facilitate. Indigenous Peoples' organizations responded with unified outrage. Letters were written to the President of the General Assembly from the co-chairs of the Indigenous Global Coordinating Group (GCG) and 66 supporting Indigenous individuals and organizations as well as from the Asia Indigenous Peoples' Caucus,<sup>45</sup> and the Latin American and Caribbean Indigenous Peoples' Caucus.<sup>46</sup> These letters decried any proposals that a co-facilitator representing Indigenous Peoples would not be required for

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<sup>44</sup><http://www.un.org/esa/socdev/unpfii/documents/wc/letter-to-pga-3-mech-jan2014.pdf>

<sup>45</sup> <http://www.aippnet.org/index.php/statements/1410-statement-from-the-asia-indigenous-peoples-caucus>

<sup>46</sup> <http://unpfip.blogspot.com/2014/03/communique-to-john-ashe-president-of-un.html>

the World Conference. Further outrage was expressed at the different rules proposed for Member States and for Indigenous Peoples: that the results of the Member State consultations would not be released to Indigenous Peoples, while the results of the consultations with Indigenous Peoples would be shared with Member States.

Citing the UN Declaration on the Rights of Indigenous Peoples and General Assembly resolution A/RES/66/296 (which established, in 2012, the guidelines for the organization of the World Conference), the GCG co-chairs, Hjalmar Dahl and Florina Lopez, wrote explicitly of the right to participation for Indigenous Peoples:

Your decision is not acceptable to us as it violates our right to participate in decisions that affect us on an equal basis with states. We are very concerned that our participation in this process is being severely curtailed making it untenable for us to continue to engage. In light of this, we would ask you to reconsider your decision in order to provide for the full, equal and effective participation of Indigenous Peoples.<sup>47</sup>

A statement released from the North American Indigenous Peoples' Caucus went a step further than the other letters and statements, calling for the cancellation of the meeting as a result of the unequal treatment of Indigenous Peoples laid out in the Aide-Memoire. The Caucus members wrote:

The North American Indigenous Peoples' Caucus operates from the foundational principle that every deliberation, decision or document, by any entity, that fundamentally affects us, our territories, our interests, or our future generations, must include our full, equal and effective participation. This principle applies no less to the decisions and organs of the United Nations than it does to any other entity...

Indigenous Peoples around the globe, including NAIPC, were clear that any such high plenary meeting would obtain the approval and participation of Indigenous peoples only if the condition of equal, full and effective participation by Indigenous Peoples was

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<sup>47</sup> <http://www.wcip2014.org/wp-content/uploads/2014/03/GCG-letter-to-PGA-4-March-20141.pdf>

assured by the United Nations. The condition of equal and effective participation was particularly crucial regarding the drafting, production and dissemination of any outcome document that emerged from the HLPM/WCIP.<sup>48</sup>

An Aide-Memoire sent out at the end of February indicated that the decision to hold separate processes, and refusal to appoint an Indigenous co-facilitator, were based on resistance from Member States in two of the five UN regions – not identified – who refused to participate if Indigenous Peoples were treated as equals to member states.<sup>49</sup> Ultimately, the World Conference took place with only Member States holding rights to participate in the deliberations, although two Indigenous “advisors” were included in the meetings. Despite providing the Alta document, which formed the basis for Member States deliberations during the World Conference, key recommendations by representatives of Indigenous Peoples were not included in the Outcome documents. Central among these were recommendations for full and equal representation at the UN and veto power regarding issues that affect Indigenous Peoples (Gilio-Whitaker 2014).

#### *UN Mechanisms for the Engagement and Rights of Indigenous Peoples*

There are three UN mechanisms with mandates to promote and monitor the protection of the rights of Indigenous Peoples. The first mechanism is the Permanent Forum on Indigenous Issues, created as an advisory council to the Economic and Social Council in 2000. The other two mechanisms receive their mandate from the Human Rights Council: the Special Rapporteur on the rights of Indigenous peoples, appointed by the High

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<sup>48</sup> <http://www.culturalsurvival.org/news/naipc-calls-cancellation-united-nations-world-conference-Indigenous-peoples#sthash.R2XAQAa0.dpuf>

<sup>49</sup> <http://wcip2014.org/wp-content/uploads/2014/03/Aide-memoire-of-PGA-26-Feb-2014.pdf>

Commission on Human Rights in 2001, and the Expert Mechanism on the Rights of Indigenous Peoples created by the Human Rights Council in 2007.

The three UN mechanisms have different mandates but consult one another and coordinate efforts to press for inclusion of Indigenous peoples in decision making, particularly within UN initiatives, draw attention to rights violations of Indigenous peoples, and promote Indigenous rights.

*The Permanent Forum on Indigenous Issues (Permanent Forum)*

The Permanent Forum on Indigenous Issues was created by the United Nations Economic and Social Council in 2000 (Resolution 2000/22). The Permanent Forum is mandated to: educate and raise awareness of Indigenous issues; to assist organizations throughout the UN system to coordinate work on Indigenous rights; and to provide ECOSOC and the UN more broadly with advice and recommendations. The Permanent Forum has sixteen members: eight are elected by Indigenous people from seven regions: Africa; Asia; Central and South America and the Caribbean; the Arctic; Central and Eastern Europe, Russian Federation, Central Asia and Transcaucasia; North America; and the Pacific. These regions are different from the usual regions used by UN and were crafted to support representation by Indigenous Peoples in a way that recognized socio-cultural similarities, which fall differently for people of Indigenous origins than current state boundaries allow. Each region elects one representative and the first three regions alternate to select one additional floating representative. The other eight representatives are selected by UN member states from the five UN regions: Asia, Africa, Latin America and the Caribbean, Eastern Europe, and Western Europe and Other States. Since the establishment of the Permanent Forum, the Member States in four out of the five regions

have taken turns sending, alternately, one or two representatives from their regions. The Western Europe and Other States region have always sent two representatives for each term.

*The Special Rapporteur on the Rights of Indigenous Peoples*

This office was first commissioned by the Human Rights Council in 2001 (Human Rights Council Resolutions 6/12 and 15/14) and has been consistently renewed since, with the latest renewal in 2007. Current areas of focus are the status of Indigenous Peoples in each region and extractive industries and Indigenous Peoples. The mandate of the special rapporteur is:

- a) To examine ways and means of overcoming existing obstacles to the full and effective protection of the rights of Indigenous peoples, in conformity with his/her mandate, and to identify, exchange and promote best practices;
- b) To gather, request, receive and exchange information and communications from all relevant sources, including Governments, Indigenous peoples and their communities and organizations, on alleged violations of the rights of Indigenous peoples;
- c) To formulate recommendations and proposals on appropriate measures and activities to prevent and remedy violations of the rights of Indigenous peoples;
- d) To work in close cooperation and coordination with other special procedures and subsidiary organs of the Council, in particular with the Expert Mechanism on the Rights of Indigenous Peoples, relevant United Nations bodies, the treaty bodies, and regional human rights organizations.

*The Expert Mechanism on the Rights of Indigenous Peoples*

The Expert Mechanism on the Rights of Indigenous Peoples, a five-member expert panel, was created by the Human Rights Council in 2007 (Resolution 6/36) with a mandate for conducting and compiling research relevant to the rights of Indigenous peoples. Members of the Expert Mechanism are appointed by the Human Rights Commission, selected for geographical diversity with the requirement to attempt to ensure representation by Indigenous people and gender equity. Although the criteria do not require the members be Indigenous, from the first appointments in 2008 through 2014, ten of the eleven expert members have been of Indigenous descent. All of the expert members appointed since 2011 have been Indigenous.

*Indigenous Peoples and International Human Rights Instruments*

Two human rights instruments are fundamental to the current status accorded to Indigenous Peoples in global bodies: ILO Convention 169 and the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP). ILO Convention 169 was established in 1989 and came into force in 1991. The UNDRIP was adopted by the UN General Assembly in 2007. Four countries -- Australia, Canada, New Zealand, and the U.S. -- votes against the UNDRIP in 2007 (and eleven abstained); however, all four countries had reversed their previous position and adopted the UNDRIP by 2010. The chief differences between the two are their legal nature and the level of state support. As a convention, ILO Convention 169 is binding on states that ratify it. This gives it stronger legal standing than the UNDRIP which, as a declaration, has no binding authority on states. The stronger legal standing of ILO Convention 169, however, is somewhat offset by the small number of states that have adopted it. The UNDRIP, albeit with weaker legal standing, enjoys the support of

the UN General Assembly while only slightly more than 10% of UN member states have ratified ILO Convention 169.

The biggest questions regarding the status of Indigenous Peoples have revolved around whether or not Indigenous Peoples are considered a “people” according to international norms and are, therefore, due a higher level of consideration for their claims. The UNDRIP has the last word, to date, using the terms “peoples” throughout; then, in Article 46, defining down that term so that it no longer appears to include rights to self-governance, autonomy, and sovereignty.

#### *ILO Convention 169*

The Indigenous and Tribal Peoples Convention, ILO Convention 169, was adopted in 1989 and came into force in 1991. Martin Nakata, Chair of Australian Indigenous Education at the University of New South Wales, describes the convention in democratic terms that speak to Dworkin’s call for equal respect and concern for subordinate groups. For Nakata, this convention is the first to be “based on the concepts of respect for the enduring nature of Indigenous and Tribal Peoples and on their right to participate in the decision-making process as it affects them in the country in which they live” (Nakata 2001,17). Convention 169 requires non-discrimination for Indigenous Peoples, safeguards for people, property, lands, and cultures, and the right to participate in decisions that affect them and in broader public governance of the country in which they live.<sup>50</sup> This convention is legally binding on the countries in which it has been ratified. However, as of 2015, this included only twenty-

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<sup>50</sup> The ILO Convention does not include a representation requirement, such as, for example, that Indigenous Peoples have representation in ILO governance.

two countries: fifteen in Latin America, four in Europe, two in Asia-Pacific, and one in Africa.<sup>51</sup>

*The United Nations Declaration on the Rights of Indigenous Peoples*

The UN Declaration on the Rights of Indigenous Peoples, adopted by the General Assembly in 2007, contains provisions that relate to autonomy and authority for Indigenous Peoples to make decisions for themselves. The articles contain language supporting the right to self-determination and autonomy (Articles 2 and 3), including to “maintain and develop their own Indigenous decision-making institutions” (Article 18) although Article 3 limits this to “internal and local affairs” and the ability to raise funds. Further provisions charge states with ensuring the protection of Indigenous Peoples’ rights to select and work through their own representatives and representative institutions and to provide “free, prior, and informed consent” before any activities or legislation that affect them, in particular, issues having to do with their lands, including relocation, taking of land or cultural, religious or intellectual property, and storage of hazardous waste on Indigenous lands (Articles 11, 19, 28, 29, and 32). In particular, Article 32 details the requirement for free, prior, and informed consent:

States shall consult and cooperate in good faith with the Indigenous peoples concerned through their own representative institutions in order to obtain their free and informed consent prior to the approval of any project affecting their lands or territories and other resources, particularly in connection with the development, utilization or exploitation of mineral, water or other resources.

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<sup>51</sup> The countries that ratified ILO Convention 169 as of 2015: Argentina, Bolivia, Brazil, Central African Republic, Chile, Colombia, Costa Rica, Denmark, Dominica, Ecuador, Fiji, Guatemala, Honduras, Mexico, Nepal, Netherlands, Nicaragua, Norway, Paraguay, Peru, Spain, Venezuela. See <http://www.ilo.org/ilolex/cgi-lex/ratifce.pl?C169> for a regularly updated list of ILO conventions and state ratifications.



*After ILO Convention 169 and the UNDRIP: The Status of Indigenous Peoples*

Marcus Colchester, anthropologist and senior policy advisor with the Forest Peoples Programme, argues that the “‘third generation’ of international human rights law [has] significantly modifie[d] the way the international human rights regime is seen as applying to indigenous peoples” (2011, 20). Summarizing the current state of Indigenous Peoples’ rights, Aguilar et al. (2010) note the lack of international consensus on the rights that Indigenous Peoples can claim against states. Even so, they describe what they view as a minimum set of rights that Indigenous Peoples can claim as a result of ILO Convention 169 and the UNDRIP:

[I]t is possible to build a framework of minimum standards for the rights of Indigenous peoples through the use of international human rights instruments, including ILO Convention No. 169 and the United Nations Declaration on the Rights of Indigenous Peoples” including the “rights to non-discrimination, self-determination, cultural integrity, property, use, control, and access to lands, territories, and resources, and to the development, participation, and social well-being, constitute the essential elements of the international standard of Indigenous peoples’ rights (91).

Colchester (2011) identifies a similar set of rights:

[I]nternational laws very firmly uphold the principle that indigenous and tribal peoples derive their rights in land from custom and their close ties with their lands. Such rights obtain independent of the actions of the States, which they may in any case predate. International conventions are also explicit that indigenous peoples have the right to exercise their customary law, to self governance and to represent themselves through their own representative institutions (20).

Dahl (2009) describes the change in the international environment after the adoption of ILO Convention 169 and the approval of the Draft Declaration on the Rights of Indigenous Peoples in sweeping terms: “the status of Indigenous peoples changed from being objects to being subjects of international law” (20).

### ***People Living with HIV and the Struggle for Representation***

UNAIDS estimates<sup>52</sup> that there were over 35 million people living with HIV in 2013.<sup>53</sup> In 2013, 1.5 million people died of AIDS, a number that has been in decline since 2005. New infections have declined since 2001; nevertheless, there were 2.1 million new infections among adults and 240,000 among children in 2013 (UNAIDS 2014a). Reflecting a new optimism, after clinical trials that demonstrated that newly infected people can expect to live an almost normal lifespan (Nakagawa et al. 2012) and that people on effective treatment have little to no risk of transmitting HIV to others (Cohen et al. 2011), the director of UNAIDS, Michel Sidibé, has called for an end to the epidemic by 2030 (UNAIDS 2014b).

Yet serious issues remain that have the potential to derail efforts to end the epidemic. To take one example, ending the epidemic requires access to medication. However, access is an on-going problem for people living with HIV. In 2014, 38% of adults and 24% of children with HIV who needed medication had access to it. Without medication, almost everyone with HIV dies within four to ten years. The biggest determinant of access to medication for a person with HIV is the country in which he resides. The lowest levels of treatment access are seen in Madagascar, where the percent

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<sup>52</sup> Based on reports from UN Member States.

<sup>53</sup> “People living with HIV” is the preferred terminology for people who have the Human Immunodeficiency Virus (HIV). While the term refers to anyone who has HIV, whether or not they have been diagnosed, it is usually understood to mean those people who have HIV and who know it. This terminology and the movement of people with HIV were both established in Denver, in 1983, when a small group of men, all living with AIDS themselves, wrote a set of principles for people with AIDS and those in communities with and providing care for people with AIDS. In the “Denver Principles,” they declared, “we are not victims, we are only occasionally patients, we are people with AIDS” (People with AIDS Advisory Committee 1983).

of people living with HIV who need medication and are able to access it is approximately 1%. Madagascar is one of thirteen countries across Asia (primarily in Central Asia, but also in the southern, western, and eastern parts of the region), Eastern Africa, and the Middle East where fewer than 20% of people who need HIV medications are able to access them. At the other end of the spectrum is Cuba, followed by five more countries, all in the Caribbean and Sub-Saharan Africa, who provide access to more than 90% of their populations who need them.

Access to medication is further correlated with being adult, heterosexual, cisgender,<sup>54</sup> of a dominant racial group, living in one's country of origin and with no history of drug use, sex work, or imprisonment (NGO Delegation 2013). In other words, people who are marginalized in multiple ways, in addition to HIV status, have less access to life-saving treatment. A report by the NGO Delegation to the UNAIDS governing board highlights two examples of this "equity deficit" faced by key affected populations<sup>55</sup> in relation to treatment:

[I]n Swaziland, a country which has successfully achieved coverage of 87%, only 33% of [gay, bisexual, and other men who have sex with men] living with HIV receive ART. In the European region where PWID [people who inject drugs] represent 59% of people living with HIV, World Health Organization studies demonstrate that this community constitutes just 21% of the total number actually receiving ART (NGO Delegation 2013, 4).

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<sup>54</sup> Cisgender refers to people who identify with the gender that they were assigned at birth.

<sup>55</sup> The phrase "key affected populations" is generally used to refer to groups that carry a disproportionate burden of HIV infections and that have a low social status. This low social status is seen as creating increased risk for HIV and decreased concern by governments for the lives of people in these groups. Although there are some differences in the populations referred to by this phrase, key affected populations are generally understood to include gay and bisexual men and other men who have sex with men, transgender women, people who use drugs, sex workers, and people who are incarcerated. Other populations sometimes included are women, children and adolescents, refugees, migrants, and internally displaced people, and Indigenous Peoples.

Similar gaps exist for gay men, particularly young gay men, transgender people, and sex workers across the world's regions (The Global Forum on MSM and HIV 2012; WHO, UNICEF & UNAIDS 2013; NGO Delegation 2013). A research report based on the experiences of gay men and transgender people in Southern Africa concluded:

[W]hile the global conversation focuses on novel approaches to HIV treatment and prevention, GMT [gay men and transgender people] struggle to obtain the most basic health services. They are isolated, criminalized, blackmailed, and beaten ... Real efforts to increase donor and national government engagement in preventing and treating HIV infection among GMT must include comprehensive human rights programming that addresses stigma and discrimination" (The American Foundation for AIDS Research (amfAR) & Johns Hopkins Bloomberg School of Public Health, 2013).

Based on an interview with Ruth Morgan Thomas, global coordinator of the Global Network of Sex Work Projects, the NGO Delegation wrote, "in countries such as Namibia, which report 91% coverage, there is strong anecdotal evidence that sex workers chose to die rather than face persecution at government ART clinics" (NGO Delegation 2013, 5).

It may seem odd that one of the two major movements for global recognition comes from a group of people united by a medical condition. Unlike the situation for Indigenous Peoples, most people living with HIV are not born into the group. While many people living with HIV share other group affiliations, for example, gay men, overall, many different communities are affected; communities made up of individual people who might never cross paths if they did not share an HIV diagnosis. Adding to the complexity, one's life chances for surviving and achieving a measure of health are dramatically different from one region of the world to another. This would seem an unstable basis for a movement, and makes the success people living with HIV have seen in gaining global recognition particularly puzzling. What similarities exist that have allowed people living with HIV to

weave their different life experiences into one organized community capable of gaining the attention and support of global institutions and organizations?

Two shared circumstances have created the fundamental motivations for this movement: first, the stigma and discrimination faced by people who test positive for HIV; second, the outcome when treatment is not accessible. Stigma, discrimination, and death became unifiers. Nussbaum's (2010) description of the workings of the emotion of disgust is instructive. She demonstrates how disgust has operated – and been manipulated -- politically to paint gay men as less than human, thus deserving of restrictions on their rights. Nussbaum links the feelings of disgust that are raised toward gay men with revulsion toward HIV and AIDS in general. Other research documents hierarchies of sympathy, within which some people who test positive for HIV, such as married women and newborn children, are considered sympathetic, or innocent, as compared to others, such as gay or bisexual men, unmarried women, people who use drugs, or sex workers, who are considered guilty or deserving of infection (Fassin 2013).<sup>56</sup>

Stigma is difficult to avoid for people with HIV. HIV is a disease that, early in the epidemic, was associated with marginalized groups – gay men, in particular, also people who use drugs and Haitians. Over time, they and other marginalized communities, including poor people everywhere, have continued to bear the brunt of infections. This has created a situation in which a disease that affects marginalized people was and continues to

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<sup>56</sup> d'Adesky (2004) compares the public reactions to SARS and HIV, concluding that the responses are dramatically different. In her analysis, people fear SARS because they fear infection, but "it is not linked to a moral judgement of human behavior". Further, d'Adesky argues that, "SARS was a matter of concern to all citizens, while AIDS is still viewed by many as a disease that is punishment for a sexual or other transgression from the social norm" (13).

be considered a judgment on their lives; whoever tests positive for this illness becomes guilty by association simply for have a disease associated with disliked groups. To some extent, people with HIV can make a choice to hide their diagnoses. Keeping the diagnosis secret could allow a person to avoid stigma, since the condition does not become obvious until one is ill and the course of illness can appear similar to other diseases. This choice for avoiding stigma, however, is difficult to survive. Mobilizing to address mistreatment based on HIV status became a way for many people to fight to stay alive.

The impossibility of escape from death was an early motivation for the civil society response among people living with and affected by HIV. Within North American and Western Europe, this response was led largely by gay men with the support of lesbians and others. Without change, gay men faced their own deaths, the deaths of lovers, and of whole communities. Lesbians, generally not HIV-positive themselves, faced the loss of gay male friends and community members and the rising hostility toward lesbian, gay, bisexual, and transgender people as many heterosexuals failed to distinguish between these groups in their newfound anxiety about AIDS and on-going anxiety about sex and gender roles.

The medications that currently keep people with HIV alive were first developed and made available in 1996. Because medications were only available for those individuals and countries that could afford them, the need for treatment, and, thus, survival, continued to motivate movements of people living with HIV. The best known of these movements was in South Africa, where people living with HIV started the Treatment Action Campaign in 1998 and worked with other community-based organizations to successfully fight both

pharmaceutical companies and President Thabo Mbeki's<sup>57</sup> government through legal action and public protests (Treatment Action Campaign 2010). These struggles continue through the current time as movements of people living with HIV in Thailand, Malaysia, India, Vietnam, Kenya, Guatemala, South Africa, South Korea, Brazil, the UK, Nepal and others organize to fight against Free Trade Agreements between their country and the U.S., Europe, or Japan that include "TRIPS-plus" provisions (Weissman 2006, Bhardwaj 2012). These provisions limit countries' rights to provide generic medications for public health reasons --rights guaranteed in the 1995 Trade-Related Aspects of Intellectual Property Rights (TRIPS) agreement and confirmed in the 2001 Doha Declaration (Farmer et al. 2013, Bhardwaj 2012).

*Brief history of the movement*<sup>58</sup>

The global movement of people living with HIV emerged in a more centralized manner than the global movement of Indigenous Peoples. For generations, Indigenous Peoples had organized resistance to colonialism and discrimination as individual sovereign nations and as networks and coalitions within national boundaries. The movement for recognition as one group of people at the global level emerged over time. For the HIV/AIDS movement, the urgency to address human rights abuses and access life saving treatment, in a time of increasing global communications and technologies, meant that the movement of people with HIV emerged in a different context and with different imperatives.

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<sup>57</sup> Mbeki's government was infamous for its embrace of "AIDS denialism," a conspiracy theory that holds that HIV does not cause AIDS and that HIV medications are deadly and the cause of AIDS-related mortality. Mbeki's refusal to provide HIV medications to people with HIV in South Africa is estimated to have led to 300,000 avoidable deaths. For further information, see Chigwedere et al. (2008).

<sup>58</sup> History of the global organizing of people living with HIV provided by Julian Hows, personal correspondence, June 21, 2013.

Coordination across countries began early, largely through friendships and the existing gay liberation networks. In some cases, global coordination happened simultaneously with the development of national networks.

The movement of people living with HIV is considered to start with the Denver Principles, articulated by a group of people with AIDS<sup>59</sup> in Denver, Colorado in 1983. This statement called for an end to discrimination, protection of human rights, and the right for people living with AIDS to be involved in the decisions made for them (People with AIDS Advisory Committee 1983). That year, groups of people living with AIDS started organizations in the U.S. (the National Association of People with AIDS) and England (the Terrence Higgins Trust).

The first international meeting of people living with HIV occurred in 1987 in London with approximately 50 participants, primarily from across Western Europe. The idea to hold the meeting came from Dietmar Bolle, a nurse specialist who was HIV-positive. The participants focused on self-empowerment, sharing information and networking. These meetings were renamed the European Meetings for People with HIV/AIDS, then renamed again in late 1990, when networks of people living with HIV in North America, Latin America, and the Caribbean organized themselves and joined the European networks in an International Steering Committee.

In 1990, the first meeting that included participants from multiple regions took place in Spain, with 550 people living with HIV in attendance, coming from 42 countries in Africa, Latin America, the Caribbean, the Pacific Islands, North America, and Europe. This

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<sup>59</sup> People were called “people living with AIDS,” rather than the “people living with HIV,” at that point in time. HIV was not identified until 1985.



meeting focused on highlighting the diversity of people living with HIV and on giving visibility to people from low income countries, people who inject drugs, and women.

Within a few years, regional networks of people with HIV developed around the world and affiliated with the International Steering Committee. In 1992, the International Steering Committee changed its name to the Global Network of People Living with HIV (GNP+). The next year, women living with HIV, including the chair of GNP+, formed a women's organization, the International Community of Women Living with HIV (ICW). From 1994 to 1997, regional networks of people living with HIV organized in Africa (NAP+), Asia (APN+), Latin America (RedLA), North America (GNP+NA), GNP Europe, and the Caribbean (CRN+).

Annual international meetings of people living with HIV took place from 1987 to 1991. The 1992 meeting was postponed after the death of Dietmar Bolle. From 1993 until 2003, meetings took place biennially. The 2005 meeting was canceled after sufficient funds could not be raised. The international meetings were held again in 2008 in Mexico City and 2012 in Washington D.C., organized by a newly-developed Living with HIV Partnership which included GNP+, ICW, UNAIDS, the International AIDS Society and other international organizations and local host partners.

In 2006, GNP+ led a consultation effort with networks of people with HIV around the world to develop a Global Advocacy Agenda for people living with HIV. The agenda was updated in 2008 and 2012 through a series of regional and web-based pre-consultations and during the international meetings in Mexico and the U.S. The 2012 Global Advocacy Agenda is organized around three pillars: universal access to HIV treatment, care, and support; the human rights of people living with HIV, including addressing stigma and

discrimination, travel restrictions, criminalization, and privacy violations; and community mobilization and organizing to build leadership and ensure the continued meaningful involvement of people living with HIV in the epidemic response (People Living with HIV Global Advocacy Agenda 2012).

Starting in 2008, GNP+ shifted its focus to community-level research and began to support country-level networks of people living with HIV to gather evidence on stigma and discrimination, human rights violations, and the meaningful involvement of people living with HIV in the national responses. People with HIV were trained in the use of evidence for advocacy and programs and supported to use the evidence they gathered. GNP+ began to compile evidence from multiple countries at the global level to use for global advocacy. Further adoption of the principle that the people most affected should be at the center of rights movements and decision-making is seen in the launch of multiple networks of populations affected by HIV.

Since the early 1990s, there has been increased organizing by key population groups. The result is an interlocking set of networks with overlapping memberships in some cases. In 1991, the International Indigenous Working Group on HIV/AIDS first met and began work to raise attention to the needs of Indigenous Peoples living with HIV. The Canadian Aboriginal AIDS Network (CAAN) was selected by the other members to host the IIWGHA and lead the global advocacy efforts. One member organization, INA--the Maori, Indigenous, and Pacific Island HIV/AIDS Foundation, describes the efforts within the Working Group to ensure meaningful inclusion for all Indigenous Peoples living with HIV, giving an example from their organization that has adopted the commitment that "Kaupapa

Maori (inclusiveness based on race, age, gender, sexuality)” be at the center of all policies (INA 2013).

In the Middle East and North Africa, the Regional/Arab Network against AIDS (RANAA) was established in 2002 to combine NGO efforts from 14 countries; establishment in 2010 of MENA Rosa, a network of women living with HIV in the Middle East and North Africa (MENA) region. Members come from Morocco in the west to Iran in the east to Djibouti in the south. The group members named themselves after U.S. civil rights hero, Rosa Parks. In their words:

MENA-Rosa is a group of women who will work for the rights of women working for dignity and love. The name of the network originates from MENA [Middle East and North Africa] for the region, and Rosa as the first black woman on a bus in the US who refused to give up her seat to a white man, starting the civil rights [movement] for black Americans. Rosa is also a feminine symbol. Our friend Zouheira started this process in Algeria seven years ago, as the first woman to raise her voice. She demonstrated to us, by her courageous actions, that we are able to have a group and to raise our voices as well. Our objectives are numerous, as we find that the particular needs of women are, in fact, different from men’s, i.e., sexual and reproductive health, children and families. The outcome would be to impact the health of the woman and her family in the MENA region.

(UNAIDS 2012, 6)

The Global Forum of Men who have Sex with Men was established in 2006. MSMGF which brings together gay and bisexual men and other men who have sex with men, advocates, and researchers to bring attention to the needs of gay men around the world and fight for their health and human rights.

The International Network of People who use Drugs was organized in 2006 to bring a voice to people who use controlled substances. They seek decent treatment and humane responses for people who use drugs and harm reduction approaches to drug policy. The

right to participation by people who use drugs in the HIV response is included in one of their founding principles:

To provide support to established local, national, regional, and international networks of people living with HIV/AIDS, Hepatitis and other harm reduction groups, making sure that active drug users are included at every level of decision-making, and specifically that we are able to serve on the boards (of directors) of such organizations and be fairly reimbursed for our expenses, time and skills (Vancouver Declaration 2006).

In July 2012, during the Sex Worker Freedom Festival in Kolkata, India, the Global Network of Positive Sex Workers and the Asia Pacific Network of Positive Sex Workers were founded to fight for treatment access and for the rights of HIV-positive sex workers. Their platform demands included: “the right to look fabulous - to do this we need better and affordable HIV drugs now;” the right to work as sex workers as well as in any other industry; an end to free trade agreements that limit access to generic medications in poor countries; to “not to be last in line for treatment or refused treatment because we are sex workers” (Tully 2012).

*Involvement in International Institutions and Organizations: the Joint United Nations Programme on HIV and AIDS and the Global Fund to Fight AIDS, Tuberculosis and Malaria*

In 1994, the member states of the United Nations created the Joint United Nations Programme on HIV/AIDS (UNAIDS) to lead global efforts to address the epidemic. The leadership of this agency is different from any other at the UN in that its governing body, the Programme Coordinating Board, includes five civil society delegates alongside delegates from twenty-two member states (on a rotating basis) and the eleven

cosponsoring organizations from within the UN.<sup>60</sup> Only the member states have voting rights on the board; however, decisions are made by consensus in practice. As stated in the Terms of Reference for the Programme Coordinating Board, “Though technically NGOs do not have “the right to take part in the formal decisionmaking process” of the PCB, in practice NGOs fully participate and are essential, respected stakeholders in decision-making processes” (UNAIDS 2008, quoting in part the Economic and Social Council, Resolution 1995/2 which created UNAIDS ).

The Global Fund to Fight AIDS, Tuberculosis, and Malaria (“the Global Fund”) was established in 2001 as a global public-private partnership to coordinate funds to address these three diseases; all treatable conditions that had become leading causes of death globally. Networks of people living with HIV, through GNP+, played a leading role in the formation of the Global Fund, creating guidance for the leadership structure, funding, and accountability of the GF and submitting this guidance as part of the NGO and Civil Society Consultation of the Global Fund. People living with HIV served on the transition team to create the GF and were instrumental in gaining two seats on the GF board of directors for people living with HIV and a requirement that people living with HIV have voting seats on Country Coordinating Mechanisms, national bodies charged with creating National AIDS Strategies and requesting, implementing, and monitoring grants from the Global Fund. GNP+ has continued to monitor and evaluate the involvement of people living with HIV in the Country Coordinating Mechanisms, providing feedback to the Global Fund and developing training materials for people living with HIV to be equipped to work with the Global Fund processes at the country level. At the 2014 to 2016 replenishment meeting

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<sup>60</sup> The cosponsors are UNHCR, UNICEF, WFP, UNDP, UNFPA, UNODC, ILO, UNESCO, UNWomen, WHO, and the World Bank.

held in Washington D.C. in December 2013, donor states and foundations pledged \$12 billion USD to fight HIV, Tuberculosis, and Malaria. This represents a 30% increase from the amount raised for 2011 to 2013; however it is significantly less than the \$15 billion that was sought to maintain programs in the countries currently receiving Global Fund grants and dramatically less than the \$87 billion estimated need for eradicating all three diseases completely. The largest contributors to the Global Fund overall are the United States, France, the United Kingdom, Japan, and Germany. In 2013, five countries that were current recipients of Global Fund grants made funding pledges to the Global Fund to demonstrate their support for the funding mechanism: Malawi, Nigeria, Mexico, India, and China (Gelfand 2013).

*People Living with HIV and International Human Rights Instruments*

There are three UN General Assembly Declarations that apply to people living with HIV: the 1996 Political Declaration on HIV and AIDS; the 2001 Declaration of Commitment on HIV and AIDS; and the 2011 Political Declaration on HIV and AIDS.<sup>61</sup> These all include a key provision related to the right to participation for people living with HIV. This provision, the GIPA principle (the greater involvement of people living with HIV and AIDS), calls for people with HIV to be included in the decisions that affect them. The GIPA principle was first articulated in a 1994 meeting of 46 governments in Paris. The statement in 1994 was founded in the 1983 Denver Principles and found a place in all subsequent UN General Assembly Declarations on HIV and AIDS. All three Declarations include attention to human rights, particularly women's human rights, freedom from discrimination, vulnerabilities of children and adolescents, and treatment people living with and affected by HIV.

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<sup>61</sup> The next UN General Assembly Special Session on HIV and AIDS will take place in 2016.

Participation rights for people living with HIV are included in three sections in the 2011 Declaration: one focused on cooperation with people living with HIV and key populations to ensure a more effective response, and calling for equal participation for people living with HIV in “social, economic and cultural activities” (para 40); one supporting the leadership and engagement of young people, including young people living with HIV (para 56); and the final one calling for the engagement of people living with and affected by HIV “in decision- making and planning, implementing and evaluating the response” (para 57).

### ***Summary***

The challenge for human rights organizing by marginalized groups is three-fold: becoming more visible could lead to backlash; pressing claims against the state and the international systems reinforces the authority of those systems; yet, limiting activism maintains the status quo which is unacceptable (see Minow 1995, Levi 1997). These challenges are particularly acute for indigenous rights organizing. Not only do rights claims against the state and international systems legitimize systems that rose to power through oppression of Indigenous Peoples, but, as Dean and Levi (2003) explain, “while indigenous people’s failure to voice the abuse of their rights invites more violations and mistreatment, the more than indigenous people are seen and heard outside of popularly conceived traditional contexts (i.e., the more they become savvy about the media, politically skilled, linked to the international community), the more they risk being seen as ‘authentic’” (2). For organizing by people living with HIV, the relationship with the state can be much less fraught. Yet, because HIV-infection occurs disproportionately among people who are already vulnerable, people living with HIV tend to come from the margins of society and lack the concern of the state for their well-being. States would have to actively commit to

transforming class divisions, employment opportunities, gender inequality, and political opportunities for disempowered minority groups to change the relationship to the state for most people living with, and vulnerable to, HIV.

Despite the challenges, adopting the global language and principles of human rights has been effective for both movements. Internally, human rights frameworks helped to shape a particular consciousness within each movement that participants are rights-bearers, even if the state within which they reside fails to recognize them as such. These frameworks have shaped the kinds of demands and language that the movements bring forward. This has required movement leaders to learn the language used by global elites and to engage in processes of translation<sup>62</sup> to ensure that human rights frameworks have resonance with the lives of people within local communities. If this translation had failed, organizing communities of marginalized peoples around the world on the basis of human rights principles would have been impossible. Externally, the human rights framework has created an entry point into global dialogues about meaningful consultation, inclusion, and representation. Notably, broad appeals for popular support have been rare for both movements. Instead, the claims for the right to participate in decisions that affect them, in essence, self-governance claims, have sidestepped the political communities within each state and been taken directly to political leaders (both national and global). This strategy reflects the extent to which translations of universal human rights principles into local understandings has lagged for general populations as well as the resonance of human rights language for marginalized groups seeking decent treatment.

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<sup>62</sup> Sally Engle Merry (2006) provides a close look at the translation process between global human rights frameworks of gender equality and action against domestic violence in local lived experiences and argues that similar processes of translation are required within any global-local advocacy movement.





## CHAPTER 7 A FRAMEWORK FOR LIBERATORY REPRESENTATION

What do we mean by community voice? We mean giving space to the people most impacted. Voice matters because so often the marginalized communities we work with have been spoken over. They're invisibilized, or even worse, hyper-visibilized – meaning they're turned into a stereotype, an image, that politicians and the mass media blame for all the ills happening in our cities. Our communities become synonymous with 'problems that need fixing', and in the process they are stripped of their humanity... We move with and work from a philosophy steeped in the principles of human rights and human dignity. The people we work with deserve a voice, a place at the table, and deserve a right to live in this city and be heard.

Desiree Evans (2013), *Women With A Vision*, New Orleans, Louisiana

The task taken up in this project is to devise a framework for representation within international institutions through which marginalized groups can move toward increased equality in self-governance. This movement toward self-governance is otherwise understood as a liberatory movement: a process of change from a situation of guardianship, within which dominant groups make decisions for marginalized groups, into a situation of political equality within which marginalized groups are able to shape the decisions that affect them.<sup>63</sup> The quote by Evans that opens this chapter articulates this vision of liberatory work with and on behalf of marginalized people.<sup>64</sup>

In creating this theory of liberatory representation, we face a set of difficult dilemmas. States systematically ignore the interests of marginalized populations within

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<sup>63</sup> Certainly, formal political equality can turn out to be too low a bar for a goal of meaningful political voice. Having as much of a voice as everyone else in shared decisions can mean, in some cases, having a great deal of influence, and, in others, having no influence at all. However, in all cases, there exist some social groups that enjoy governmental attention to their interests. Political equality, as used here, refers to the enjoyment of equal influence in decision-making in comparison with those social groups, whether those groups are large or small in their particular societies.

<sup>64</sup> *Women with a Vision* is a non-governmental organization established in 1989 by African American women in New Orleans as a women's health collective focused on the needs of local women of color living with and affected by HIV.

their borders, or worse, become violators of the human rights of these populations. Attempting to bypass states by seeking representation in global bodies is one approach to remedy the lack of state concern. However, once marginalized groups leap over the state to the global system, they find themselves still within state-centric processes, and they face the risk that their advocacy will lessen the legitimacy of the very institutions upon which their hopes for equal treatment are pinned.

On the positive side of the liberation tally sheet, increased global representation can reduce stigma, increase attention to the needs of populations historically excluded from meaningful voice, and build more inclusive communities of shared fate. Yet, a series of minus marks must be added to this tally sheet, reflecting that such representation can reinforce the status quo and more deeply marginalize the most vulnerable people within the group. Further negative marks are required to recognize the disproportionate and heavy burden placed on marginalized groups who seek to participate in decision making places, as they must pull together the time, funding, and skills to struggle for the meaningful attention to their needs that dominant groups – already better resourced – can take for granted. Seen in this light, civil society work on behalf of marginalized groups reflects a privatization of work that governments ought to do to provide equally for their citizens. However, if civil society organizations do not emerge and pressure both governments and international institutions, then work for the political equality of marginalized groups is left undone.

As Abbott and Gartner (2012), theorists and legal practitioners in the field of international institutions, write, “the optimal design of international institutions to

confront twenty-first-century global challenges is an increasingly urgent question” (34).  
What, then, are we to do?

From the literature of theorists and practitioners of global representation, described in the previous chapters, three goals for a process of liberatory representation can be identified. These are:

1. Decisions that affect the members of a marginalized group are made with their meaningful participation (Equal Respect and Concern).
2. The marginalized group is perceived as a fellow decision maker in, rather than object of, processes of governance (Status).
3. New coalitions develop within which marginalized groups are partners and their interests are included (Partnership).

Each of these goals must be understood in the broadest sense to fundamentally include the diversity of subgroups that exist within a marginalized group, including gender, race and ethnicity, sexual orientation, class, age, and other groups depending on the context. Taken together, the goals promote the outcomes of dignity and political equality for marginalized groups, and sustainability for their on-going participation as political equals in governance.

The dilemmas inherent in global representation, alongside these three goals, are summarized in Table 4. To the extent that a process, through its design and implementation, can achieve these goals and address these dilemmas, it leads toward liberatory outcomes. Each goal and each dilemma should be viewed as a continuum within which decisions can be made that give more or less power to subordinated groups that can be used to shape the conditions under which they live.

**Table 4: Foundations for a Framework for Liberatory Representation**

Goals	Dilemmas
<p>Equal Respect and Concern: Decisions that affect the members of a marginalized group are made with their meaningful participation.</p>	<p>Institutional Legitimacy: States are not responsive to needs of those marginalized; however, the more effectively states are bypassed, the greater the risks to the legitimacy of international institutions. If these institutions are discredited, the situation for the marginalized can worsen.</p>
<p>Status: The marginalized group is perceived as a fellow decision maker in, rather than object of, processes of governance.</p>	<p>Subordinated groups within: Marginalized group representation offers democratic benefits; however, these may accrue to the most privileged in the group and risk further marginalization of those who are subordinated within the group.</p>
<p>Partnership: New coalitions develop within which marginalized groups are partners and their interests are included.</p>	<p>Undue Burden: Group representation creates an undue burden on marginalized groups, who already face challenges of participation that dominant groups do not, and makes civil society do the work that states ought to do; however, the alternative is to leave marginalized groups without representation.</p>

There are four aspects that comprise any representation framework: composition, mandate, selection, and working methods (Thies 2009). This chapter will examine these four aspects in light of their potential to meet the goals of liberatory representation (influence, status, partnership) and to address the dilemmas (institutional legitimacy, those subordinated within the group, and undue burden). The purpose is not to provide one comprehensive theory of representation; but, rather, to shed light on issues that require attention no matter the context or situation and to offer a theoretical approach and

practical methods for addressing these issues. After describing the framework, this chapter will conduct an analysis of two current representation processes in global institutions, the United Nations Permanent Forum for Indigenous Issues (Permanent Forum) and the Joint United Nations Programme on HIV/AIDS (UNAIDS), to determine the degree to which their functions meet liberatory criteria.

### ***Sketching a liberatory framework of representation***

There are four critical elements in the development of a representation process that can shape the extent to which the goals of liberatory representation are met and the dilemmas within global representation are adequately addressed. These elements, as described by Thies (2009) are: the composition, the mandate, the selection processes and the working methods. These four elements determine what can be done, by how many and which people, and with what authority? Although some of the elements are interconnected in practice, this chapter examines each element separately to elucidate its distinct properties and potential for a liberatory practice.

#### *Composition*

The composition of a representative body includes the number of seats; how the seats are distributed; and, when applicable, where the body fits within a larger organization. These structural decisions affect the likelihood of meaningful influence versus tokenism. Decisions about composition shape the opportunities that different subgroups within a marginalized group have to join the representative body; the partnerships that can develop across oppressed and dominant groups within the representative body, through their shared work; and the partnerships that different marginalized groups can forge with each other within the representative body. Decisions

about composition also affect the burden on communities and on individual representatives, as representative bodies that are poorly structured require additional labor to address issues adequately and manage coordination.

**Table 5: Composition**

Goals	Dilemmas
Equal Respect and Concern	Subordination within
Partnership	Undue Burden

If the composition is to meet liberatory goals, then it needs to be structured in a way that ensures influence to representatives from marginalized groups. This does not mean that marginalized groups win on every decision, but, rather, that the representatives from these groups have a meaningful opportunity to sway the outcomes. It does mean that marginalized groups do not always lose. When the composition is structured to ensure influence, then partnership also becomes possible. Representatives from dominant groups have a reason to partner with representatives from marginalized groups to get decisions passed.

The composition of a representative body addresses two dilemmas: it can ensure that the democratic benefits from representation also accrue to those subordinated within marginalized groups and, to a lesser extent, it can reduce the costs of participation for representatives. The way that representation is structured affects the burden experienced by the representatives from marginalized groups. If the number of group representatives is large enough, then the emotional weight of representing a group that is looked down on is

lessened for each. A larger group also shares the labor of communicating and consulting with constituents and representing the breadth issues that a marginalized group faces.

For inclusion of subordinated groups within the larger group, the structure of representation must be designed to recognize that multiple groups and viewpoints exist within affected communities. Without specific attention to differences, only the most privileged group members will end up holding positions and speaking for all. Seats can be distributed in such a way that a diversity of representatives, specifically including those from groups that are subordinated within the marginalized group, will hold them. This can be done through assigned seats for specific communities or an overall requirement for diverse representation, or a combination of both. Some parliamentary processes have designated seats for members of Indigenous or ethnic minorities, including for Maori representatives in New Zealand, Indigenous representatives in Colombia, and scheduled castes and tribes in India (Bird, 2004). Processes with designated seat structures support the voices of those who are less dominant within the group. The purpose of these structures are to protect against further advantaging more privileged group members at the expense of those further subordinated within the group. The establishment of formal seats within governance for different subgroups provides greater inclusion and accountability. The further advantaging of more privileged groups is demonstrated by Scholte and co-authors (2011) in case studies of global organizations. In their study, organizations from the global south were rarely included in global organizations' decision-making processes. Their inclusion only happened when seats were dedicated for them. Otherwise, all of the civil society voices that participated in decision-making processes came from the global north.



A priority for the Global Fund to Fight AIDS, Tuberculosis, and Malaria (Global Fund), when established in 2001, was to ensure that Country Coordinating Mechanisms (CCMs) would be composed in such a way that stakeholders from multiple sectors would work together to address the three diseases in their country. CCMs are decision-making bodies that must exist within each state that wishes to access Global Fund grants (Global Fund, 2015). The Global Fund devised a differentiated structure -- including members from government, the private sector, multilateral and bilateral officers, and civil society -- that is based on a combination of assigned seats and overall diversity requirements. The stated goals for the structure are to “operationalize human rights principles that include non-discrimination, gender equality and participation of key affected populations” (Global Fund, 2105). In its current guidance documents, the Global Fund requires gender equality within the CCM membership, a minimum of 40 percent of CCM members from civil society, and at least one member who is living with and representing people with HIV. If the country plans to request funding for tuberculosis or malaria programming, then the CCM is also required to have members representing people living with or affected by those diseases. For civil society organizations, having 40 percent of the seats set aside creates influence within the CCM and provides opportunities to partner with other partners.

The reservation of one seat for people living with HIV or one of the other two diseases is intended to ensure the ability of those most affected, but also more stigmatized and generally less funded, to participate. However, setting aside only one seat for people living with HIV and one for those with malaria or tuberculosis has not been sufficient in most settings to give these groups enough influence to affect outcomes or to develop

partnerships with the more established CCM members.<sup>65</sup> Despite the success of the PLHIV movement globally, within countries, it has often been difficult for members of PLHIV networks to be included in CCMs or treated as partners in the HIV response. An evaluation in 2004 recommended that CCMs include no fewer than two people living with HIV and seek to have a minimum of 10 percent of members be people living with HIV (Policy Project 2004). A later evaluation of CCMs in eight countries, conducted in 2008, found that civil society members overall often lacked respect from other members, needed technical skills, and doubted their own capabilities (ICASO 2008). Further, CCMs, and their civil society members, generally excluded organizations from more marginalized groups (such as those representing women, transgender people, or gay men) in favor of mainstream, better funded, organizations already connected with governments (ICASO 2008). In response to these and internal evaluations, the Global Fund strengthened CCM requirements to include documented membership of key affected populations on CCMs and defines these populations broadly to include “women and girls, men who have sex with men, transgender persons, people who inject drugs, male and female and transgender sex

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<sup>65</sup> However, in a few countries, the opposite situation has prevailed. Civil society representatives have been active participants in CCM meetings, effectively pressing for attention to the most affected communities and communicating their sense of urgency to the full CCM (ITPC 2008). This situation supports Kanter’s (1977) predictions in her early research on tokenism. Kanter is better known for her analysis of the effects of structural factors on the behavior of marginalized minorities within larger groups, specifically, that in demographically skewed or tilted environments (in percentages of 15% or less, certainly, but to an extent until representation reaches around 40%) women in male-dominated workplaces will adopt male norms and limit actions considered supportive of women or gender equality. This is the starting point for most work on tokenism today, whether in agreement or opposition to Kanter’s arguments (Childs and Krook 2008). However, Kanter received less attention for her predictions that, in some cases, individual women with a pronounced feminist consciousness would disregard the pressures toward tokenism and advocate for women and gender equality despite the expectation that they behave differently (Childs and Krook 2008, Kanter 1977).

workers and their clients, prisoners, refugees and migrants, people living with HIV, adolescents and young people, vulnerable children and orphans, and populations of humanitarian concern” (Global Fund 2011, 8). As of 2015, CCMs must demonstrate annually that they meet the requirements for inclusion of people living with HIV, and, in some places malaria and tuberculosis, and key affected populations, as a condition of acquiring and keeping their funding.

### *Mandate*

The mandate of a representative body indicates the extent of its authority and the boundaries of its jurisdiction. Mandates for representative bodies range from advisory functions to governing responsibilities. The mandate affects the extent to which two democratic goals for liberatory representative processes are met: influence over decisions that affect the group and increased status for members of marginalized groups. The stronger the mandate is, the greater the ability of the representative body to disrupt the status quo. Therefore, the mandate brings to the surface the tensions between increasing the political voice for marginalized groups and maintaining the support of currently dominant actors.

**Table 6: Mandate**

Goals	Dilemmas
Equal Respect and Concern	Institutional Legitimacy
Status	

If the mandate is to meet liberatory goals, then it must be shaped in a way that ensures that marginalized groups can influence the decisions that affect them and that

positions them as political equals in addressing shared problems and challenges. Mandates to serve as a consultative or advisory body offer only the possibility of influence for marginalized groups. These kinds of mandates force marginalized groups to take a gamble with their resources because there is no assurance that, if marginalized groups provide their time and expertise, their interests will be considered in the final decisions. Stronger mandates, in terms of influence and status, are those that charge marginalized groups with providing recommendations, drafting proposals, or making decisions. When bringing representative processes to the global level, the mandate must balance the increased power for marginalized groups with the authority under international law of states -- and states alone -- to negotiate common agreements.

Different representative processes strike different balances regarding the level of influence accorded to marginalized groups. No processes within the U.N. system allow civil society representatives a deciding role in directives that are binding on states. By contrast, within other global institutions, such as the Global Fund to Fight AIDS, Tuberculosis, and Malaria (Global Fund), representative bodies exist within which civil society organizations have an equal voice with governments. These differ from U.N. bodies in their voluntary nature – no government is forced to apply to the Global Fund for grants - and their mandate to recommend and oversee programs and funding for the three diseases. States may disagree with the human rights requirements for Global Fund grants but they are free to simply disregard these unless they choose to seek funding. By contrast, the process for developing the Sustainable Development Goals (SDGs) that will guide the global development agenda after 2015 was been inclusive of civil society organizations in its formative stages. However, controversies between U.N. member states have continually

flared over the question of when civil society should or should not be allowed to comment. More recent stages have excluded civil society organizations despite support from a number of states (IISD 2014, Open Letter 2014).

### *Selection processes*

The composition of a representative body establishes which groups are eligible to serve as representatives. The selection process determines who has the authority to decide, from among those groups, who will actually represent these constituencies. For processes that include civil society representatives, selection options range from elections to appointment.

**Table 7: Selection process**

Goal	Dilemma
Partnership	Subordination within

The composition of the representative body and the way that the selection process is designed, together, will determine whether a diversity of voices from marginalized groups will be included or whether those who are most privileged within the group will become the representatives for all. Within marginalized groups, the most privileged are those with characteristics most similar to those valued by dominant social groups, such as heterosexuality, male masculinity, wealth, or higher education. Those most privileged are also the most likely to be known by those outside of the group. Therefore, selection processes that rely on appointment are likely to perpetuate the status quo.

By contrast, holding elections, in which marginalized groups choose their own representatives, supports their self-determination and their dignity as active participants

in discussions about the issues that concern them. In addition, when groups are responsible for selecting or nominating their own representatives, group members are more likely to develop partnerships with a broader range of other people within their group. Prospective representatives communicate with other group members who may be differently situated, facilitating stronger connections and understandings of the range of concerns held by the group.<sup>66</sup>

If the representative body is structured so that the seats are open to anyone in the group, then elections will most likely default to the most dominant group members. However, if seats are dedicated to specific subgroups within a marginalized group – such as women, people with disabilities, gays or lesbians, working class, or young people within racial or ethnic minority groups -- then elections can be set up to allow the members of each of these subgroups to select who will represent them. Within global decision-making bodies, dedicated seats are most commonly based on geography, although the pressure from civil society for involvement in health issues has resulted in dedicated seats based on disease condition within the HIV/AIDS response. For example, the Global Fund board of directors includes three seats<sup>67</sup> for civil society delegations based on geography and disease condition: one for developing country NGOs, one for developed country NGOs, and one for the communities delegation<sup>68</sup> (Global Fund 2014). Each seat has one voting

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<sup>66</sup> In her work on women's representation, Sawer (2000) demonstrates the broadening effect for women leaders of interactions with other women from different circumstances.

<sup>67</sup> The Global Fund refers to each seat as a "constituency" to recognize that the board member is not there in an independent function but as the representative of a broader constituency (Global Fund 2014).

<sup>68</sup> The communities delegation is made up of people living with or affected by HIV, tuberculosis, or malaria from around the world.

member and a larger delegation that advises and supports the voting member and participates in Global Fund committee work.

At the country level, the Global Fund requires that multi-stakeholder Country Coordinating Mechanisms (CCMs) be established to apply for Global Fund grants. Representatives from civil society and those from communities living with and affected by the three diseases, as well as any academic or private sector representatives, are “to be selected by their own constituencies based on a documented, transparent process, developed within each constituency” (Global Fund 2013, 2).

In Kenya, a commitment to making selection meaningful for affected communities has led to a multi-stage selection process, funded by the CCM. Selection starts with a country-wide community education process, followed by regional elections. At a national forum, the regional representatives select their representatives to the CCM (Long & Duvvury 2011).

### *Working methods*

The working methods of a representative body encompass all of the activities -- such decision-making processes, consultations, and communication -- and norms -- such as the amount of deference groups give to constituents or, in global bodies, to powerful states -- that representatives perform in their role. How a representative body works affects the extent to which it meets all three liberatory goals: where outcomes demonstrate equal respect and concern for marginalized groups; whether marginalized groups see an increased status as a result of their inclusion; and whether new relationships are developed between marginalized and non-marginalized groups that allow on-going collaborations on issues of shared concern. The working methods shape the burden that

marginalized representatives shoulder in their struggle to gain equal political concern for their communities. In addition, the working methods that are adopted will determine whether groups that currently hold power – most notably for this project, member states in the U.N. system -- support the representative process or decide to exit through physically leaving the body or simply by withdrawing their participation and support.

**Table 8: Working methods**

Goals	Dilemmas
Equal Respect and Concern	Institutional Legitimacy
Status	Undue Burden
Partnership	

The presence of marginalized groups in a decision-making body does not lead automatically to liberatory outcomes. The working methods matter. Although representatives of historically excluded groups are present, they continue to bear the stigma of marginalization that exists outside of the decision-making body (Williams 1998). Their presence, by itself, does not erase the biases against them that other representatives hold. Attention to political equality requires working methods that promote the influence of marginalized representatives, treat them clearly as equals, and encourage partnerships between marginalized and other representatives. A look at two practices illustrates how working methods can be directed toward liberatory ideals: first, rules for making decisions and, second, activities that strengthen marginalized groups' interactions with the larger body.



The rules for how decisions are made, and who is allowed to participate in making them, demonstrate the status that different groups hold. The democratic challenge for marginalized groups is that they are perpetually ruled over by others. If representation is to lead toward political equality, then it must support marginalized groups to meaningfully participate in the adoption of decisions that affect their group. Full and equal voting rights for representatives of marginalized groups demonstrates a formal political equality within the group; however, voting rights within a majoritarian system leave marginalized groups in the same vulnerable position that they hold within countries. That is, the outcomes of a formally egalitarian system are systematically unequal. A system of voting based on simple majorities will be insufficient to achieve liberatory ideals. More substantive political equality for marginalized groups can be achieved through decision-making rules that call for consensus, super majorities, or consent from those most affected. As one example, the Global Fund board of directors has decision rules designed to ensure an equal voice for donors and implementers. All board members are assigned to either the donor bloc (developed countries and private sector representatives) or the implementer bloc (developing countries, NGO and community representatives). For a board decision to be approved, it must gain support from two-thirds of the members of each bloc (Global Fund 2013).

Within international institutions, the rules for decision making, above all other norms and activities, are the working methods most likely to draw the ire of states. Consensus is the process relied upon throughout the U.N. for intergovernmental decisions. Among states, consensus provides a fundamental recognition of the equal right of all to decide for themselves about the rules that apply to all and it creates decisions that are

legitimated through cooperation among nations. Disruption of the international system of consensus among states, through providing voting or other decision-making rights to non-state actors, creates the risk of delegitimizing the decisions that are made and reducing the commitment of individual states to the project of cooperative global governance. This creates a conundrum for civil society, and especially for the most marginalized groups within civil society. International institutions can provide opportunities for political voice that are limited, or denied, domestically. Yet, if the local legitimacy for decisions made by these institutions is lost, then what looked like political equality may turn out to be an expensive exercise without effects.

Inclusion of civil society within the decision-making bodies of international institutions is a fairly new phenomenon. The effects of this inclusion on the perceived legitimacy of decisions are largely unknown. Some current processes, including those that include civil society as part of consensus processes within UNAIDS, have led to decisions from which individual states disassociate themselves or express concern that the conditions under which they agreed to participate in international institutions have been violated. Whether the contested decisions will ultimately be ignored, because of the lack of full support from all states, or whether the decisions, once adopted, will gain legitimacy, with the dispute forgotten, still remains to be seen.

Another set of working methods that lend themselves to liberatory outcomes for marginalized groups focuses on activities to build partnerships among and within marginalized groups, to learn about issues affecting different subgroups, to adopt a set of shared priorities, and to strategize and assign activities in order to reach those priorities. These activities require funds and meeting space to be provided by the larger decision-

making body. One consistent theme across descriptions and evaluations of the participation of marginalized groups in decision making is the importance of funded pre-meetings and caucus meetings. For example, civil society organizations met to develop shared recommendations for the Global Fund leadership framework before joining the Transitional Working Group negotiations that created the Global Fund (Global Fund 2013). This practice was seen as valuable and has been continued. Before each board meeting, the Developing Country NGO Delegation, the Developed Country NGO Delegation, and the Communities Delegation meet with each other and with the current Global Fund board leadership (Long and Duvvury 2011). In Indigenous Peoples' advocacy, Dahl (2009) describes such pre-meetings for Indigenous Peoples as "absolutely necessary," writing, "the lesson learned from the process of drafting the Declaration was that Indigenous peoples would have increased opportunities for making a constructive impact on the process if the pros and cons of key issues were analysed prior to the meeting." (90). Similarly, Tulley (2013), from the Asia Pacific Network of Sex Workers (APNSW) explains the importance of separate pre-meetings for sex workers when invited to consultations with the World Health Organization or other international bodies:

[I]n June 2013, sixteen sex workers attended a consultation with the World Health Organisation (WHO) in Accra Ghana to develop an implementation tool to operationalise the guidance on Prevention and treatment of HIV and other STIs for sex workers in low- and middle-income countries... NSWP [the Global Network of Sex Work Projects] held a pre-meeting the day before the consultation started. This enabled sex workers to critique each section of the draft, compile a list of non negotiable points and to develop a strategy for how we would approach the two day consultation. This "sex worker only" session is critical to getting the most out of the consultation. In fact, when NSWP or APNSW meet with UN on important consultations, we now insist on them funding a pre-meeting as a part of the overall process.<sup>69</sup>

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<sup>69</sup> Blog post, "Forging partnerships between sex workers and scientists is important," written for the Asia Pacific Network of Sex Workers. Available at:

Separate meetings for representatives of marginalized groups help to equalize their power to advocate for their groups in larger forums. Advocacy efforts are strengthened by these meetings, as representatives have confidence that they are working from a shared strategy, that they are not alone in their assessment of what is needed, and that they understand the critical points of the discussion and where differences – and word traps – may lie. Caucuses with other marginalized representatives, whether before or during the larger meetings, are also crucial for reducing the emotional burden from both being and representing stigmatized and vulnerable people.

***Evaluating two processes for representation of marginalized groups***

The United Nations Permanent Forum on Indigenous Issues (Permanent Forum) and the Joint United Nations Programme on HIV and AIDS (UNAIDS) are the foremost international institutions providing representation to marginalized people (Indigenous Peoples and civil society organizations by or for people living with and affected by HIV, respectively). While both organizations share a history based in struggles for recognition by marginalized people, their representative processes, and their legitimacy, arise from different rationales. Indigenous Peoples occupy a unique position in the international system by virtue of their prior, and continuing, inhabitation and political organization within spaces that were later appropriated by states.

States in the international system have sought to signal support for the language of self-determination, as it appears in the U.N. Charter, the Friendly Relations Declaration, and other significant international instruments, in respect to the rights of Indigenous Peoples

without threatening their own privileges and territories. This contradictory approach long predates, and is reflected in the articles of, the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP). The opening articles in the UNDRIP acknowledge Indigenous Peoples as “peoples” and affirm that “Indigenous peoples have the right to self-determination. By virtue of that right they freely determine their political status and freely pursue their economic, social and cultural development” (Article 3). However, by the end of the Declaration, this expressed right to self-determination is so deeply restricted as to be rendered nearly meaningless: “Nothing in this Declaration may be...construed as authorizing or encouraging any action which would dismember or impair, totally or in part, the territorial integrity or political unity of sovereign and independent States (Article 46, para 1).” This final article contradicts the text language in Article 3 guaranteeing Indigenous Peoples the right to “freely determine their political status” and it stands in contrast to the ways in which this right has been previously applied.<sup>70</sup> As Engle (2011) argues, this final statement effectively “seals the deal: external forms of self-determination are off the table for Indigenous peoples, and human rights [rather than rights as “peoples”]

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<sup>70</sup> The UN Charter language describes the purpose of the UN as “to develop friendly relations among nations based on respect for the principle of equal rights and self-determination of peoples, and to take other appropriate measures to strengthen universal peace”(Article 1, para 2). Further defining self-determination and emphasizing its importance, the Charter language stresses that, when a country holds control over colonies or territories, fundamental to this trusteeship is to promote “progressive development” by the people in those colonies or territories toward “self-government or independence,” based on “the freely expressed wishes of the peoples concerned” (Article 76). The Friendly Relations Declaration (UNGA Resolution 2625 (XXV), 24 October 1970) specifies the meaning of equal rights and self-determination of peoples as the rights of all peoples to “freely to determine, without external interference, their political status and to pursue their economic, social and cultural development” and that the outcomes of this free determination can include “the establishment of a sovereign and independent State, the free association or integration with an independent State, or the emergence into any other political status” (Principle 5),

will largely provide the model for economic and political justice for Indigenous peoples” (147). As a result, the Permanent Forum can be seen as a vehicle for human rights: one that recognizes some rights of Indigenous People to participate in decisions that affect them but stops short of challenging state’s control over territory or global decisions.

**Table 9: Comparison of the UN Permanent Forum for Indigenous Issues and the Joint UN Programme on HIV/AIDS**

	Permanent Forum	UNAIDS
Composition	16 members with seats allocated regionally. Eight members are decided by government and eight are nominated by civil society. The role is of individual expert rather than representative.	33 members, of which 22 are UN Member States, allocated regionally, and five represent non-governmental organizations, allocated regionally. Six seats represent the eleven UN Co-Sponsor organizations. Two NGO seats are reserved for organizations from developed countries and those with economies in transition and three seats are reserved for organizations from developing countries. All roles are considered to be representative of constituencies.
Mandate	Advisory to the UN system. Equal voting rights for government and civil society members.	Governance of the Joint Programme.
Selection	Governments select one half of the members. The others are appointed by the ECOSOC president based on the recommendations from regional Indigenous organizations.	The five civil society seats are held by ten civil society organizations from five regions. The NGO Delegation sets the criteria, conducts recruitment, and selects representatives.
Working Methods	Annual open forum with testimonies from Indigenous organizations and other stakeholders. Recommendations are determined in private sessions and publicly announced. Civil society	The NGO Delegation participates in UNAIDS Programme Coordinating Board (PCB) meetings and working groups but does not have the right to vote. Co-sponsors do not vote either. The PCB norm is that decisions

	observers use opportunity to network with states and leaders.	are made by consensus. Civil society observers provide interventions during PCB meetings at the discretion of the chair. The NGO Delegation meets privately before each PCB to determine strategy and assign work and also holds separate pre-meetings with civil society observers, the Co-Sponsor Coordinating Committee, the UNAIDS Secretariat, and some Member State delegations.
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Compared to the role for Indigenous civil society in the Permanent Forum, the situation for civil society, in general, and people living with HIV in particular, within the UNAIDS governance structure, is less complicated. Rather than attempting to assert a sovereign right to be included, these civil society organizations argue for inclusion on grounds such as protecting the dignity of people stigmatized by the disease, needing to protect the human rights of especially vulnerable groups, and offering expertise in programming to make global efforts effective. These arguments were used to draft and then gain support for the GIPA principle (the Greater Involvement of People Living with HIV) in political declarations and commitments from 1994 forward.<sup>71</sup> Support for the inclusion of NGOs in the governance of UNAIDS was based on both civil society pressure and U.N. member states adoption of, and subsequent reiterations of support for, the GIPA principle. If we use the framework of liberatory goals and dilemmas for representation of

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<sup>71</sup> The Paris Declaration of the Paris AIDS Summit, 1994; 2001 Declaration of Commitment on HIV/AIDS (A/Res/S-26/2); 2006 and 2011 Political Declarations on HIV and AIDS (A/Res/60/262, A/Res/65/277).

marginalized groups as the criterion, how do the Permanent Forum and UNAIDS measure up?

*UN Permanent Forum on Indigenous Issues*

The UN Permanent Forum on Indigenous Issues was established in 2000 by the UN Economic and Social Council with a mandate to:

- provide expert advice and recommendations on Indigenous issues to the Council, as well as to programmes, funds and agencies of the United Nations, through the Council.
- raise awareness and promote the integration and coordination of activities related to Indigenous issues within the UN system.
- prepare and disseminate information on Indigenous issues.

(ECOSOC resolution 2000/22)

The composition of the Permanent Forum was designed to provide equal status for governments and Indigenous communities, with eight members nominated by governments and ratified by ECOSOC and eight nominated by Indigenous communities and appointed by the ECOSOC president. Government-nominated members are selected based on the five U.N. regions: Africa, Asia, Eastern Europe, Latin America and the Caribbean, and Western Europe and Other States. Indigenous members are nominated by Indigenous organizations in seven regions: Africa; Asia; Central and South America and the Caribbean; the Arctic; Central and Eastern Europe, Russian Federation, Central Asia and Transcaucasia; North America; and the Pacific. The eighth Indigenous seat rotates between the African, the Asian, and the Central, South American, and the Caribbean regions.



The following analysis draws on the founding documents, an assessment of the Permanent Forum in light of its mandate (Schulte-Tenckhoff & Khan 2014), an evaluation of the legitimacy that the forum has among Indigenous community leaders (Thies 2009), and an analysis of Indigenous people's involvement and opportunities for resistance within the Permanent Forum (Lindroth 2011). An overview of the information comparing Permanent Forum structure and processes to the liberatory goals and representation dilemmas is shown in Table 7.

**Table 10: The UN Permanent Forum on Indigenous Issues and Liberatory Goals and Dilemmas**

Goals	Permanent Forum
<p>Equal Respect and Concern: Decisions that affect the members of a marginalized group are made with their meaningful participation.</p>	<p>Within the Permanent Forum, Indigenous members have influence. They are able to shape Permanent Forum recommendations. Permanent Forum decisions are made by consensus and all members have equal standing. Testimony from Indigenous observers can affect the recommendations of Permanent Forum. However, the limited mandate for the Permanent Forum means that the overall influence Indigenous Peoples have is greatly constrained.</p>
<p>Status: The marginalized group is perceived as a fellow decision maker in, rather than object of, processes of governance.</p>	<p>Indigenous Peoples are recognized as valued co-participants in the U.N. system. Within Permanent Forum, government and Indigenous appointees have equal status.</p>
<p>Partnership: New coalitions develop within which marginalized groups are partners and their interests are included.</p>	<p>The Permanent Forum Members develop relationships with governments and U.N. agencies. It is unclear whether any of these relationships have led to the inclusion of interests of Indigenous Peoples in national or global decisions.</p>
<p>Dilemmas</p>	

<p>Institutional Legitimacy: States are not responsive to needs of those marginalized; however, the more effectively states are bypassed, the greater the risks to the legitimacy of international institutions. If these institutions are discredited, the situation for those marginalized could grow worse.</p>	<p>The Permanent Forum is designed to protect Member State authority, through the mandate, which allows only an advisory role, and the structure, which sets aside one half of the seats for government representatives.</p>
<p>Subordinated groups within: Marginalized group representation offers democratic benefits; however, these may accrue to the most privileged in the group and risk further marginalization of those who are subordinated within the group.</p>	<p>Diversity of representatives is assured through regional representation; however, there are no other mechanisms to ensure equity in representation for other subgroups of Indigenous Peoples.</p>
<p>Undue Burden: Group representation creates an undue burden on marginalized groups, who already face challenges to organizing that dominant groups don't, and makes civil society do the work that states ought to do; however, the alternative is to leave marginalized groups without representation.</p>	<p>The limited mandate also means a lower workload; however, there is little evidence that Permanent Forum activities improve conditions for Indigenous Peoples at either global or country levels.</p>

*Goal 1: Equal Respect and Concern*

The experience of equal respect and concern, as a liberatory goal for marginalized people, is defined narrowly for this project. To be considered liberatory, the representative process must be designed in a way that ensures Indigenous Peoples a voice in shaping the outcomes of decisions that affect them. Within the Permanent Forum, the outcomes are mixed. Certainly, Indigenous Peoples have influence within the Permanent Forum;

however, because of the Permanent Forum's limited mandate, in general, that influence does not extend to decisions that affect them in the global system or by governments. An end of the year message from Dalee Sambo Dorrough, Chairperson of the Permanent Forum, described the clashing approaches to Indigenous influence:

Fortunately, the Permanent Forum and Indigenous peoples generally enjoy support from UN member states at the international level. However, too often, little support or prioritization to implement Indigenous human rights norms at the national and domestic level is shown. And, in some extreme cases, we have member state support in key areas internationally, while at home, in these same states, Indigenous peoples are being forcibly removed from their lands and their very survival and security threatened both individually and collectively.  
(Dorough 2014)

When Indigenous leaders were interviewed about the effectiveness of the Permanent Forum as a vehicle for Indigenous influence, their concerns outweighed their positive evaluations. Notably, the Indigenous leaders with the most international experience had the lowest expectations of what was possible within the U.N. system and were, therefore, generally more pleased with what the Permanent Forum has achieved (Thies 2009). Areas that Indigenous leaders credited as providing opportunities for influence were the mechanisms for Indigenous observers to present interventions – thus allowing them the opportunity to raise issues of importance for Indigenous Peoples and to attempt to shape the agenda from the floor -- during the Permanent Forum's annual two-week meeting and the opportunities, through these interventions, to press states regarding their human rights violations;<sup>72</sup> and the perceived increased accountability for UN

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<sup>72</sup> It is important to note that that the Permanent Forum has no authority to monitor state's activities toward their Indigenous populations; therefore, interventions that challenge states about their mistreatment of Indigenous populations are designed to "name and shame" rather than to lead to any kind of official sanction (see Lindroth 2014).

organizations in terms of their attention to the needs of Indigenous Peoples (Thies 2009). Further, Indigenous leaders from Asia and the Arctic indicated that the nomination process for the Indigenous members of the Permanent Forum was a source of influence as they were able to decide, for themselves, who would hold the Permanent Forum seat. However, leaders from the other regions, where coordinated region-wide consultation processes have not been established, indicated less faith in the nomination process (Thies 2009). For those regions, multiple nominations are put forward and the ECOSOC president decides which one to appoint.

The structure of the Permanent Forum has created concerns about the limited influence available to Indigenous Peoples. Concerns focus on a sense that the mandate to gather information and advise U.N. agencies is too limited, and more authority is needed for the body to truly represent Indigenous issues. In her 2009 research, Thies concluded, “the Forum’s inability to generate outcomes that make a difference for the living conditions of Indigenous communities [is] due to its weak mandate, or its perceived unwillingness due to a domination by states” (2009, 38). Thus, Schulte-Tenchkhoff and Khan (2014) describe sympathetically the “constant attempts by the Permanent Forum to expand its mandate,” including though defining itself as the implementing body for UNDRIP (680). These attempts have included calls, largely unheeded, to Member States to provide regular reports on their compliance with their obligations under UNDRIP.

There are further restrictions on the influence of Indigenous Peoples that go beyond concerns about the mandate. Permanent Forum members serve as independent experts and not as formal representatives of Indigenous communities. Therefore, the extent of influence that Indigenous organizations have depends entirely on whether or not the

Permanent Forum members choose to engage with them. Indigenous leaders expressed disappointment that they had few opportunities to influence the annual sessions. While observers can provide testimonies to the Permanent Forum, Thies (2009) documented an “elevated number of comments which evaluated participation opportunities for observers negatively” (23) including the following quote from one observer: “[L]ast year in New York, I was never able to intervene because there was no time left...Although there were 14 days, we [were] just assisted to listen to the work of the institutions of the United Nations that work with Indigenous population[s]” (translation by Thies, 23).

### *Goal 2: Status*

Reducing stigma and improving the status of marginalized people is another representation goal. Have Indigenous Peoples seen an improvement in their status as a result of the existence and work of the Permanent Forum? Certainly, the composition of the Permanent Forum, which assigns equal status to Indigenous and non-Indigenous participants, is a recognition of Indigenous Peoples as leaders and experts in addressing their own issues. Generally, Indigenous leaders agree that the Permanent Forum has improved the political status for Indigenous Peoples. When asked, they describe the existence of the Permanent Forum as providing recognition of Indigenous rights, with this recognition most clearly indicated by the right to nominate their own representatives – an activity generally seen as a prerogative of states within the U.N. system (Thies 2009). In the working methods of the Permanent Forum, Indigenous observers are treated as equals with Member State and U.N. agency observers, although leaders report that it is on-going struggle to achieve equal treatment in practice. As one leader told Thies (2009):

“I think it's fair to say that we, we don't really feel like we're observers. From the time that we started in, and like many other Indigenous groups we felt that we had a right to be here, and a right to be heard, and a right of equality with the states that are here. And that has been an ongoing struggle from the outset to ensure that we are being treated as peers, to ensure that we are not being excluded and marginalized by states” (32).

The experience of working as equals has an effect on Indigenous communities as well as the non-Indigenous government and U.N. leaders. This includes education about the larger set of human rights to which all human beings are entitled and that are larger than the rights that come from one's nationality. Reflecting on the experience for Indigenous participants in the Permanent Forum, a Latin American Indigenous leader described it as, “[A] source for consciousness raising among different Indigenous communities themselves, of their representatives. That is, awareness of human rights, not Indigenous rights, human rights, that can be applied to our communities” (Thies 2009, 33, translation mine).<sup>73</sup> Insights into different human rights agreements strengthen the internal sense of political equality for Indigenous participants and provide further justifications that they can use in negotiations with UN member states and UN agencies.

Despite the formally equal working relationship between Indigenous and non-Indigenous participants, the nature of working within a system developed to protect state sovereignty restricts the ability for Indigenous Peoples to be treated as equal participants in practice. Analyses by Lindroth (2011) demonstrate the extent to which status, for Indigenous Peoples, is dependent on compliance with UN processes and acceptance of state sovereignty. She notes the different unwritten rules for inhabiting the physical space of the

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<sup>73</sup> The quote in Spanish reads as follows: “También ha sido una cantera para la adquisición de conciencia de las mismas comunidades indígenas, de sus representantes. o sea conocer los derechos humanos, no derechos indígenas, derechos humanos que pueden ser aplicados para nuestras comunidades” (Thies 2009, 33).

meeting rooms and for making interventions. In Lindroth's words, "It is clearly visible how the UN is an organization of states and how Indigenous peoples have to find their own space, both figuratively and concretely, somewhere among the states and the UN agencies" (550). Initially, Indigenous observers were required to find seats where they could be behind the Member State and UN agency observers. In addition, unlike the other observers, they were not provided with official name cards. They would, instead, draw them by hand for themselves. Indigenous observers launched a successful campaign for inclusion among the other observers in the seating arrangements; however they have not been able to change the pre-registration requirement in which they must self-identify as non-governmental organizations rather than as sovereign nations (Lindroth 2011).

While the formal rules provide parity for Indigenous and non-Indigenous interventions, the practice is different. "An experienced Indigenous activist made the following observation about his disillusionment with the UN during the sixth PF session: 'We're conforming to the UN but the UN is not conforming to us'... At a side event during the same session, another Indigenous representative expressed her frustration at the strict time limits for Indigenous statements in the plenary sessions: 'We weigh very carefully every word so that everything we want to say can be said in three minutes' "(Lindroth 2011, 549). Time limits are certainly the prerogative of the chair, and are commonplace in governance forums. However, the time limits are not applied evenly, such that "states enjoy ample speaking time and the chair will not usually interrupt their statements as he or she does those of Indigenous peoples if they exceed the allowed time" (Lindroth 2011, 550). Thus, it seems that the existence and the practices of the Permanent Forum have increased the status of Indigenous Peoples, especially through the symbolism of establishing a

Permanent Forum and making Indigenous Peoples visible as leaders in addressing global problems; yet, this status is contingent on an acceptance by Indigenous Peoples of treatment as less than sovereign in their own affairs and as less equal than others within the workings of the Permanent Forum.

### *Goal 3: Partnership*

The development of partnerships within and across marginalized groups and between marginalized groups and those with more social power is a fundamental goal for liberatory representation. The Permanent Forum has been largely successful in this regard. The area in which it has not met liberatory goals is predictable based on its structure: partnerships have not developed between Indigenous communities and the Permanent Forum (Thies 2009). On the other hand, the Permanent Forum has established a process for observer interventions that has been effective in building partnerships across Indigenous communities. To reduce the number of interventions, a rule was developed that gives first priority in the speaking order, along with five minutes rather than three minutes to speak, to regional representatives. As a result, regional groups have formed coalitions, identifying shared concerns, in order to create regional interventions (Thies 2009, Lindroth 2011). The existence of the Permanent Forum, and its annual meetings, creates spaces for Indigenous organizations to lobby governments and to network with each other. Indigenous leaders indicate increased capacity from their participation especially in terms of their effectiveness when working with their governments back home and their ability to coordinate with other Indigenous organizations (Thies 2009). One further positive partnership effect of the Permanent Forum, according to Indigenous leaders, occurs between the Indigenous Members and those appointed by Member States. As they debate



their recommendations, they build relationships and learn from each other about their respective situations and constraints (Thies 2009).

*Dilemma 1: Institutional Legitimacy*

Marginalized people seeking, through global institutions, a greater ability to participate in decisions that affect them face a dilemma. Global institutions, whether in the U.N. system or separate, are successful to the extent that states support them. Yet, the work of marginalized people in global forums is to press for changes, predominantly to be made by states. The more pressure that marginalized people place on global institutions, the greater the challenge to states' authority. This means that marginalized people are faced with a tension between attempting to gain as much political power as they can while trying to determine what might push states so far that states withdraw their support for global institutions. For example, in 2009, the Permanent Forum published a General Comment to demonstrate their understanding that UNDRIP article 42 expanded their mandate to include monitoring the Declaration's implementation. Not only did some Member States adamantly oppose this reading of the UNDRIP, but their comments sought to describe the UNDRIP as a document with little authority for the countries that ratified it. As Schulte-Tenchkhoff and Khan explain, "What comes across in our analysis of the Permanent Forum is the mostly unintended negative impact the Forum's permanent quest for a mandate has generated for the normative content of the Declaration on the Rights of Indigenous Peoples as a whole, as well as its chances of acquiring a binding force" (694).

At the same time, acknowledging U.N. bodies as legitimate intergovernmental organizations can be particularly challenging for Indigenous Peoples. As Lindroth (2011) describes, "Engaging in a political arena that is based on state sovereignty is problematic

for Indigenous peoples in many ways. However, it is impossible for those peoples to defend their rights and further their claims without having to negotiate with states,” and, further, their, “claims for justice by states function to promote and legitimate state sovereignty, as the claims are forwarded on the states’ terms and within the states’ systems, as is the case in the UN” (Lindroth 552). More than this, the kinds of rights claims that Indigenous Peoples can make are limited by the preferences of states in the global system. Schulte-Tenchkhoff and Khan (2014), write “the Permanent Forum sustains the limitation of collective rights to their least controversial aspect – namely human rights exercised by individuals in community with other members of their group, as opposed to group rights claimed by non-state groups as such” (687). In the U.N. system, Indigenous Peoples have to play by the rules set up by states and perform the recognition of state sovereignty, including the sovereignty of the states within which they claim rights and territory, in order to seek redress for past violations and attention to current needs.

*Dilemma 2: Subordinated groups within civil society*

Representation processes that are designed for the inclusion of marginalized groups can have an unintended consequence of highlighting the voices of those most privileged within the group and further marginalizing others within the group. This is a serious concern for the Permanent Forum, within which the only diversity requirement is for members from different geographic regions. Although the UNDRIP specifically names Indigenous women, young people, children, the elderly, and people with disabilities as populations requiring specific attention, there are no requirements in either the founding ECOSOC resolution or subsequent Permanent Forum recommendations for their representation in the Permanent Forum. To create a stronger voice, Indigenous women,

young people, and people with disabilities, who attend Permanent Forum meetings as observers, have self-organized their own caucuses. In these caucuses, they identify issues common to their group and draft joint statements to bring the attention of the Permanent Forum members to their concerns (Cooper 2014). Since 2002, when the first Permanent Forum members took their seats, 79 individuals have served. Of these, 44 percent were women and 56 percent were men, with gender equality increasing over time. Since 2011, there have been equal numbers of women and men on the Permanent Forum. No analysis is available that has examined ages, migrant experience, education levels, occupations, sexual orientation, gender identity, incarceration history, or socio-economic status of NGO representatives. In addition, Indigenous leaders express concerns that smaller Indigenous organizations do not have an equal chance at sending a representative to the Permanent Forum (Thies 2009).

### *Dilemma 3: Burden*

The burden carried by Indigenous members, emotional or physical, is not discussed in any of the literature that evaluates or discusses the Permanent Forum. Yet, a burden clearly exists for both the Permanent Forum members and the observers. Permanent Forum members serve as volunteers yet spend two weeks in annual meetings. In addition to the formal meetings, their responsibilities include participation in preparatory meetings, the creation of background reports, review of meeting documents, and responses to issues that arise throughout the year. To be heard at the annual meeting, Indigenous peoples' organizations must dedicate staff time away from their other work as well as raise funds for travel and for accommodation in New York City. To help address the financial burdens related to travel, and to make it possible for Indigenous Peoples to be able to attend

Permanent Forum meetings, the Office of the United Nations High Commissioner for Human Rights (OHCHR) operates a Voluntary Fund for Indigenous Population, with applications due each September or October (Permanent Forum 2007). The Voluntary Fund offsets some, but not all, of the costs for Indigenous organizations and requires a substantial amount of advance planning for meetings that generally take place the next May.

*The Joint United Nations Programme on HIV and AIDS (UNAIDS)*

The Joint United Nations Programme on HIV and AIDS, established through ECOSOC Resolution 1994/24, was created to coordinate the work of the multiple agencies within the U.N. to address the HIV epidemic. Six agencies (UNICEF, UNDP, UNFPA, UNESCO, WHO and the World Bank) were the original co-sponsors of UNAIDS; that number increased to eleven by 2012.<sup>74</sup> UNAIDS was the first U.N. body to formally include civil society organizations in its governing board. Most of the details for the Joint Programme were established in 1995 (ECOSOC 1995/2), including the guidelines for civil society involvement (detailed in the Annex to the resolution). The unusual nature of a U.N. body with civil society organizations included in its governance is clear in the 1995 resolution. The Annex explicitly notes: “These arrangements for the participation of non-governmental organizations are not to be regarded as setting a precedent” (ECOSOC 1995/2, Annex).

The Programme Coordinating Board (PCB), as the UNAIDS governing board is named, is made up of 22 Member States, the eleven co-sponsor organizations,<sup>75</sup> and five civil society organizations. The Member State seats are distributed by regional groupings

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<sup>74</sup> As of 2015, the 11 UNAIDS co-sponsoring organizations are: ILO, UNDP, UNESCO, UNFPA, UNHCR, UNICEF, UNODC, UNWomen, WFP, WHO, and the World Bank.

<sup>75</sup> Increased from the initial six co-sponsors.

and the civil society seats are divided into two seats for NGOs from developed countries and transitioning economies and three seats for NGOs from developing countries. Only Member States are allowed voting rights in the PCB; however, following U.N. practices, all decisions are made by consensus.

ECOSOC resolution 1995/2 describes the limits of NGO participation:

Non-governmental organizations would be advised of the terms and conditions of their participation. It would be made clear to them that such participation would include:

A seat at the table with 6 representatives of the Committee of Co-sponsoring Organizations<sup>76</sup> and the 22 Member States;

Non-governmental organizations would be able to speak;

Non-governmental organizations would have no negotiating role;

Non-governmental organizations would not participate in any part of the formal decision-making process, including the right to vote, which is reserved for representatives of Governments;

(ECOSOC 1995/2)

The final condition in the list has been subject to some controversy regarding when “formal decision-making processes” commence. The NGO Delegation and most member states have interpreted this condition broadly, with NGO Delegates allowed to speak and deliberate with other PCB members until the moment comes when there is a call by the Chair for consensus. Other member states interpret the final condition more narrowly to mean that NGO Delegates should not propose decision points or engage in discussions or deliberations once decision points have been proposed. In 2013, the PCB Chair sought legal counsel to resolve this controversy. U.N. legal counsel gave his opinion that the NGO

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<sup>76</sup> The number of co-sponsoring organizations has increased steadily. In 2012, UN Women joined, bringing the number of co-sponsors, and seats at the PCB, to eleven.

Delegates could participate in all discussions until the point at which the chair sought to confirm consensus or held a vote.<sup>77</sup> Since that time, a détente has taken place by which PCB members defer to the Chair regarding when to call on NGO Delegates (NGO Delegation 2013b).

The UNAIDS guiding principles, developed by the PCB, reflect the multiple concerns of the different stakeholders -- states, U.N. agencies, and civil society -- that seek to shape the work of UNAIDS:

- Aligned to national stakeholders' priorities;
- Based on the meaningful and measurable involvement of civil society, especially people living with HIV and populations most at risk of HIV infection;
- Based on human rights and gender equality;
- Based on the best available scientific evidence and technical knowledge;
- Promoting comprehensive responses to AIDS that integrate prevention, treatment, care and support; and
- Based on the principle of non-discrimination. (UNAIDS 2015)

While part of the full PCB body, the NGO Delegation has a self-identity that includes a specific function within the PCB. The mission statement created by the NGO Delegation articulates this function, describing its mission as:

To bring to the PCB the perspectives and expertise of people living with, most affected by, and most at risk of, vulnerable to, marginalized by, and

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<sup>77</sup> The opinion of legal counsel was based on his reading of a clear differentiation in the founding documents between NGO Delegates and civil society observers; a difference which would largely disappear if NGO Delegates were only allowed to speak. Further, legal counsel indicated that states maintained their decision-making rights through their exclusive right to vote (NGO Delegation 2013b). Some Member States indicated disagreement with the legal counsel's opinion but they have not, as of early 2015, brought their opposition back to the floor of the PCB.

affected by HIV and AIDS, as well as civil society and nongovernmental entities actively involved in HIV work, in order to ensure that their human rights and equitable, gender-sensitive access to comprehensive HIV prevention, treatment, care and support are reinforced by the policies, programmes, strategies and actions of the PCB and UNAIDS (NGO Delegation 2012).

NGO Main and Alternate Delegates have established norms by which they identify themselves as one NGO Delegation,<sup>78</sup> rather than a group of individual or regional activists; hold themselves responsible for consulting with civil society, rather than operating as individual experts; make decisions by consensus and commit themselves to support the consensus when interacting outside of the Delegation; and choose not to operate in a hierarchy that differentiates between members and alternates. The longest-serving member from each region is technically considered the Main Delegate, and the junior member is the Alternate Delegate; however there is no difference in status in practice within the Delegation or in interactions with the PCB.

The following analysis draws on the founding resolutions and organizational documents (ECOSOC 1994/24, ECOSOC 1995/2, the Modus Operandi of the Programme Coordinating Board of the Joint United Nations Programme on HIV/AIDS (UNAIDS), 2010, and the Terms of Reference for the NGO Delegation to the UNAIDS PCB, 2012), a programme-wide evaluation of UNAIDS (Poate et al. 2009), and an independent review of civil society participation in the UNAIDS PCB (Middleton-Lee 2012). In Table 8, an overview of the information comparing UNAIDS' structure and processes to liberatory goals and dilemmas is shown.

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<sup>78</sup> The label of "NGO Delegation" appears neither in the ECOSOC founding resolutions nor in the UNAIDS PCB Modus Operandi. However, the decision to name themselves in this manner has influenced others on the PCB to also adopt the label. Similarly, Indigenous Peoples have created a group identity and status for the observers who show up for the Permanent Forum meetings, naming that group the Indigenous Caucus.

**Table 11: The Joint UN Programme on HIV and AIDS and Liberatory Goals and Dilemmas**

Goals	UNAIDS
<p>Equal Respect and Concern: Decisions that affect the members of a marginalized group are made with their meaningful participation.</p>	<p>NGO Delegates participate in setting the agenda for each PCB meeting, bringing forward key issues, proposing recommendations, and engaging in dialogue with the goal of finding consensus among PCB members. Civil society observers can raise issues themselves and work through the NGO Delegation to bring proposals to the PCB.</p>
<p>Status: The marginalized group is perceived as a fellow decision maker in, rather than object of, processes of governance.</p>	<p>The consensus process used by the PCB to make decisions creates an almost equal status for NGO Delegates.</p>
<p>Partnership: New coalitions develop within which marginalized groups are partners and their interests are included.</p>	<p>The NGO Delegation has been recognized for its partnerships with Member States, the UNAIDS Secretariat and co-sponsors. Recently, the NGO Delegation has found common cause with Developing Country member states on particular issues related to trade and development and other social and economic rights.</p>
Dilemmas	
<p>Institutional Legitimacy: States are not responsive to needs of those marginalized; however, the more effectively states are bypassed, the greater the risks to the legitimacy of international institutions. If these institutions are discredited, the situation for the marginalized can worsen.</p>	<p>This is challenging for the NGO Delegation. The level of influence combined with the level of concern extended to the most marginalized groups has led to opposition toward the Delegation by more conservative member states.</p>
<p>Subordinated groups within: Marginalized group representation offers democratic</p>	<p>The NGO Delegation has become more diverse over time in response to criticism. Intentional recruitment has led to the greater inclusion of</p>



benefits; however, these may accrue to the most privileged in the group and risk further marginalization of those who are subordinated within the group.	representatives who are living with HIV or who come from the most marginalized populations. ECOSOC resolution 1995/2 established regional requirements. The Delegation has subsequently set further requirements for inclusion of people living with HIV and key populations within the Delegation.
Undue Burden: Group representation creates an undue burden on marginalized groups, who already face challenges to organizing that dominant groups don't, and makes civil society do the work that states ought to do; however, the alternative is to leave marginalized groups without representation.	There is a heavy burden of work for NGO Delegates and their organizations. Organizations commit to volunteering 10 hours (25% full-time equivalent) per week. Staff support for the Delegation has been provided since 2008; however, even with these staff, the resources available are significantly less than those available to other PCB members.

*Goal 1: Equal Respect and Concern*

This democratic goal for liberatory representation asks whether a process provides meaningful opportunities for marginalized groups to influence the decisions that affect them. Certainly, the structure of a process does not determine everything about the level of influence that will be wielded as poor recruitment and selection efforts or a work burden that is too heavy can counteract positive structure. It is doubtful, though, that representatives will be influential consistently if the process is not designed in ways that support this. Designing global decision-making bodies that will allow real influence by marginalized people is a relatively recent undertaking. Even so, it appears that the design of the NGO Delegation provides useful lessons in how to meet this goal within a state-centric institutional structure.

To be sure, the NGO Delegation's successes have never been in battles that they fought against a united front of U.N. member states. It is unclear what would happen in that

circumstance, but the evidence to date highlights two factors that contribute to the NGO influence. First, different U.N. member states find the NGO Delegation useful for pressing their interests at different times, so the NGO Delegation can be understood as influential to the extent that their interests align with some powerful states or blocs of states. Second, there has never yet been a situation in which the NGO Delegation sought a goal and found no state support. This may reflect a setting in which states so completely dominate the institution that civil society muzzles its concerns. However, the multiple compromises made between the NGO Delegation, the U.N. co-sponsors, and the states demonstrate that the NGO Delegates do press unsuccessfully for decisions that they hope to see adopted. Indeed, it is more likely that the issues that the Delegation sees as important enough to champion are recognized as similarly important by at least some states at the table.

Two practices have been instrumental in securing influence for representatives of marginalized communities within UNAIDS. One is the custom of making decisions through consensus rather than voting. As Poate et al. (2009) note in the Second Independent Evaluation of UNAIDS, “one of the key aspects of how the PCB operates is not defined in the *modus operandi*. This is the practice of the PCB issuing decisions reflecting a consensus amongst the participants and deliberately not voting on issues” (Annex 8, para 3.3). There have been recurrent pushes from some individuals and organizations in civil society for voting rights for the NGO Delegation (Middleton-Lee 2012) while others in civil society have argued that the consensus process is acceptable, or even preferable (Poate et al. 2009). The commitment to consensus means that every seat at the PCB can be influential in the decisions that are adopted.

The second practice that has been instrumental for the NGO Delegation is their participation in agenda setting for the PCB. The NGO Delegation has pushed for, and taken advantage of, opportunities available to shape the agenda. They have been successful in gaining the opportunity to present an annual NGO report on a topic of concern for civil society and through participation on the PCB Bureau, the executive body that creates the actual agenda for each meeting (Middleton-Lee 2012). In addition, the Delegation has engaged in agenda-setting through participation in PCB working groups, and through creation of internal working groups, to focus on the board work of ensuring institutional accountability and transparency. These activities happen largely out of the light of media attention and are labor intensive, however, the watchdog role on budgets and accountability for implementation of PCB decision points demonstrates that the NGO Delegation is willing to share the burden of board work and provides the NGO Delegation with influence on the funding and decisions critical to civil society.

Within the PCB meetings, delegates continue their work to raise issues and frame the dialogue in ways that are inclusive of marginalized groups. They use their position to present data and share information from their own experience and that of others in civil society. The review of civil society influence on UNAIDS, found that “[r]epresentatives from all stakeholder groups speak passionately about the NGO Delegation’s role as a reality check to the Board’s proceedings – which, otherwise, risk being overly theoretical and political...They can ‘shift’ the discourse – by providing real life evidence, perspectives and opinions.” (Middleton-Lee 2012, 5).<sup>79</sup>

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<sup>79</sup> See, for example, a video-recording of the intervention by Joel Nana, an NGO Delegate from Cameroon, representing the South African organization, African Men for Sexual Health and Rights. In the video, from 2012, Nana responds to the opposition by some Member

Practical demonstrations of the effectiveness of the NGO Delegation in shaping outcomes can be seen in changes the delegates successfully sought to the PCB guiding principles, including that PCB work be “based on the meaningful and measurable involvement of civil society, especially people living with HIV and populations most at risk of HIV infection” (19<sup>th</sup> PCB) and “based on the principle of non-discrimination” (24<sup>th</sup> PCB) (Middleton-Lee 2012). These principles are included in the preamble to all PCB decision points. The NGO Delegation is described in the 2012 evaluation as having effectively heightened attention to human rights and the needs of most marginalized communities in the UNAIDS 2011-2015 strategy and in the 2011 United Nations Political Declaration on HIV/AIDS. However, the Delegation has recorded its disappointment at failing to convince Member States to include (a) reform of criminal laws focused on people living with HIV in the UNAIDS strategy and (b) attention to the human rights of transgender people in the 2011 Political Declaration (Middleton-Lee 2012).

In the UNAIDS Second Independent Evaluation, Poate et al. (2009) described the influence that the NGO Delegation had on the PCB decisions, during a particularly contentious meeting in 2004 on HIV prevention strategy. Because of intense lobbying and discussions before and during the meeting, decisions were adopted that focused on meeting the needs and protecting the human rights of those people most vulnerable to the disease. These proposed decisions included a comprehensive list of these groups and were passed

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States to language calling for human rights protections for key affected populations in all countries: <http://www.youtube.com/watch?v=DeYoGpoPGxE>. The other NGO Delegates, and civil society observers from different regions, are seen standing in support as Nana speaks. At the conclusion of his remarks, the video scans the room and shows some participants in Member State delegations standing, as well as applause by what appears to be a majority of Member State representatives to the PCB.

after strenuous debate and initial opposition among some strong Member States. Opposition focused on different aspects of the strategy, including evidence-based approaches on condoms; harm reduction strategies for people in prisons and those who inject or use drugs (such as needle and syringe exchange, opioid substitution therapy); and a focus on protecting human rights throughout all aspects of the prevention strategy (23).

Similarly, the 2012 evaluation described effective advocacy within the PCB meetings:

[T]he NGO Delegation has used PCB agenda items to advocate for the specific needs and rights of individual key affected communities. The Delegation – often facing considerable political opposition from some Member States – has pushed for the strongest rights - based language that would be supported by the majority of PCB members, reflect international standards and be useful for further civil society advocacy within countries and regions.

(Middleton-Lee 2012, 27)

The review and evaluation identified only a few areas where the NGO Delegation was seen as not adequately influential. The first area of concern was the lack of voting rights, although, as described above, there are mixed opinions regarding how much voting rights matter in practice (Poate et al. 2009, Middleton-Lee 2012). The other area of concern was about the post-2015 global development agenda. Respondents perceived the NGO Delegation as lacking the ability to influence the negotiations and as having insufficient power to bring other civil society voices into the process (Middleton-Lee 2012).

### *Goal 2: Status*

To what extent have marginalized communities affected by HIV seen their status increase as a result of their representation in the PCB? Within the PCB, there are clear indications that representatives of these marginalized communities have experienced

increased status over time.<sup>80</sup> This increased status approaches, but does not reach, equal treatment. The reasons for the remaining inequalities have less to do with maintaining the hierarchies that exist outside the decision-making body and more to do with the inter-governmental structure of any U.N. body. As described in the previous section, where equal status does not exist is in voting rights, which are extended only to Member States.

The status improvement gained by the NGO delegates is demonstrated by their inclusion in the PCB bureau and regular meetings with the UNAIDS Executive Director and governance team, the PCB Chair and Vice-Chair, the Co-Sponsor Coordinating Committee (Middleton-Lee 2012). Further, the NGO Delegation invites a number of Member States to meet with them before each PCB meeting (Middleton-Lee 2012). The invitation itself does not show improved status. What does is the number of states that schedule these meetings: customarily the Latin American states, the U.S. government, the Nordic states, and other European states. The African states also allow the African NGO delegates to join them for a briefing. In a further mark of improved status, the NGO Delegation was originally, but is no longer, called upon last in the speaking order of PCB members. The new order has been labeled an “equitable speaking order among the Programme Coordinating Board members, including the NGO Delegation” (NGO Delegation 2008, para 10).

In 2012, the evaluation of UNAIDS includes a telling statement from a Member State that “Now, the Delegation is not just ten individuals, but a united group that also has thousands and thousands of others behind them” (Middleton-Lee 2012, 16). This provides a possible explanation for the increased status of the NGO Delegation. The evaluation credits the delegates with creating a strong identity and shared goals within the Delegation

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<sup>80</sup> At the country level, no evaluations have been conducted of changes in status for people living with or affected by HIV as a result of their participation in global decision-making.

that have lead to higher quality interventions and created a clearer sense among Member States that the Delegation is representative of civil society organizations.

*Goal 3: Partnership*

Two kinds of partnerships are important for a system of liberatory representation: those between marginalized communities and more dominant social groups and those among different marginalized communities and subgroups. The inclusion of civil society in the PCB has allowed both of these kinds of partnerships to develop. Representatives of Member States and heads of U.N. agencies are the dominant social groups operating in these settings. Through opportunities to meet with Member States and co-sponsors, the NGO Delegation has identified where their interests align with other representatives. For example, the NGO Delegation has worked with Member States from Europe, Latin America, and North America to press for language supporting the human rights of people living with HIV and gay men and other men who have sex with men, and, to some extent, sex workers and people who use drugs. Recently, the Delegation made common cause with the African nations (and Iran which generally aligns itself with the African nations) to get decision points addressing intellectual property and free trade agreements adopted by the PCB (NGO Delegation 2015).

The structure for NGO participation in the PCB, combined with the rules adopted by the NGO Delegation for their own conduct, create opportunities for better understanding and coalition development between different communities affected by HIV. Within the Delegation, the ECOSOC rules for geographical diversity leads to cross-education about specific regional situations. The Delegation's commitment to inclusion of people living with HIV and those from most-affected communities brings more education to each member

about the circumstances that different communities experience. Since the first delegation in 1993, representatives have come from networks of people living with HIV, women living with HIV, sex worker networks, drug user networks, and young people's networks, as well as organizations in the fields of human rights, sexual and reproductive health, women's health, LGBT rights, access to medication, housing and anti-poverty initiatives, legal services, harm reduction for people who use drugs, journalism, faith communities, immigrant health and rights, and humanitarian medical and emergency relief (NGO Delegation 2014c).

Beyond the increased support between communities that occurs within the NGO Delegation, other civil society groups have more opportunities to work together and learn from one another because the Delegation exists. These opportunities occur at country and regional levels when the NGO Delegates hold pre- and post- PCB consultations and briefings with interested civil society organizations. They also take place at the PCB, where the NGO Delegation holds a briefing for all civil society observers before the meeting starts and daily debriefings throughout the meeting. The meetings provide the chance for the Delegates and observers to coordinate strategies and also for observers to build relationships and strategies with one another (Middleton-Lee 2012).

### *Dilemma 1: Institutional Legitimacy*

Within the PCB, the tension that arises between voice for marginalized groups and legitimacy for international institutions is clear. Member States challenge the level of participation by civil society to a greater extent at the UNAIDS PCB than they do at the meetings of the Permanent Forum on Indigenous Issues. This difference is likely due to the different levels of influence each body holds. Civil society board members within the PCB



physically sit at the same governance table with member states and participate jointly with member states in setting the agenda, proposing decisions, negotiating outcomes, and evaluating implementation. Indigenous Members in the Permanent Forum also sit together with the Permanent Forum members appointed by Member States, jointly craft the agenda, and cooperate to determine their recommendations to ECOSOC. However, the Permanent Forum serves in an advisory, rather than decision-making, capacity. Consequently, civil society Delegates to the PCB have greater opportunities to directly influence decisions that affect Member States and the U.N. agencies.

Three of the nine UNAIDS PCB Member States who were interviewed for the 2012 review expressed concerns about the influence of NGO Delegation within the PCB. Their criticisms of the NGO Delegation focused on the priority that the Delegation gave to human rights and key populations within the PCB. Among other concerns, these Member States complained that the Delegation's choices of topics for their annual report to the PCB overly emphasized key populations and human rights at the expense of other aspects of the epidemic that might be common to everyone (Middleton-Lee 2012). This exemplifies the dilemma at hand: while these Member States critiqued the report topics, the civil society respondents who were interviewed for the review gave high marks (greater than 90%) to the report topics. In fact, civil society respondents gave higher approval scores to the report topics than to almost any other question measuring the NGO Delegation's or UNAIDS' effectiveness (Middleton-Lee 2012, 5). As described above, in 2013, some Member States brought a formal challenge to the NGO Delegation's right to propose decision points

to the PCB -- a challenge that was sent to U.N. legal counsel for a review and was decided largely in favor of the NGO Delegation (NGO Delegation 2013).<sup>81</sup>

A greater issue for the legitimacy, and therefore, the stability, of UNAIDS as an inter-governmental body arises from decisions by a few Member States to disassociate themselves from specific decisions adopted by the PCB. Like other UN bodies, the PCB normally operates through consensus, with formal negotiations over contentious points proceeding until agreement is reached. However, the commitment to this consensus process has been challenged by actions at recent meetings.<sup>82</sup> From the 26<sup>th</sup> meeting, in 2010, to the 31<sup>st</sup> meeting, in 2012, of the PCB, the Iranian representative noted five times that the Islamic Republic of Iran formally disassociated itself from decision points that were adopted. In the same time period, the Arab Republic of Egypt disassociated itself three times, generally overlapping with the Iranian dissents.<sup>83</sup> The disassociation took the form of the following, from the 30<sup>th</sup> meeting of the PCB:

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<sup>81</sup> Member state opposition to the NGO Delegation's proposal of decision points arose in response to an NGO report focusing on "treatment access for gay men and other men who have sex with men, transgender people, sex workers and people who inject drugs: communities that persistently struggle for visibility and access to health services in many contexts" (NGO Delegation, 2013b).

<sup>82</sup> An earlier approach to a Member State's opposition to decision points can be seen in the treatment of the U.S. delegation in 2005. The PCB approved Decision 8.6 of the 17<sup>th</sup> meeting of the PCB that took notice of the U.S. government's statement that supporting needle and syringe exchange as a harm reduction approach for people who inject drugs was incompatible with national laws and policies and that the U.S., therefore, could not be expected to fund such programs.

<sup>83</sup> In 2010, regarding Decision 12 of the 26<sup>th</sup> meeting of the PCB, on "Reducing HIV transmission among men who have sex with men and transgender people," the Islamic Republic of Iran disassociated itself.

In June 2012, regarding Decision 6.1 of the 30<sup>th</sup> meeting of the PCB, "Follow-up to the thematic segment [HIV and Enabling Legal Environments] from the 29<sup>th</sup> PCB meeting," on the Arab Republic of Egypt and the Islamic Republic of Iran disassociated themselves.

The Arab Republic of Egypt and the Islamic Republic of Iran disassociate themselves from those parts of this Decision Point that may be interpreted as recognition, protection or promotion of unethical/illegal behaviours; or may contradict with cultural, moral and religious values, national sovereignty, and legal and social systems of the countries concerned. Accordingly, the Arab Republic of Egypt and the Islamic Republic of Iran shall not be bound by any results related to or arising from the abovementioned parts.

(Decision 6.1 of the 30<sup>th</sup> meeting of the UNAIDS PCB, 2012)

The first two occasions took place before the 2012 evaluation of civil society participation in the PCB was complete. Member States referred to the conflict with concern. By contrast, NGO Delegates expressed some support for the processes of disassociation, as reported in the evaluation:

[T]he 2012 Review identified widespread concern about tense dynamics between some members of the PCB. This is seen to have contributed to a scenario whereby – to conclude some highly sensitive agenda items and prolonged debates – some Member States have started to ‘dis-associate’ themselves from decision points. Some stakeholders fear that, as a representative of a Member State put it, “the time for universal consensus has gone” – weakening the power of PCB decisions. However, others, including many in the current NGO Delegation, welcome that ‘dis-association’ enables the PCB to maintain relatively strong language, such as about key affected communities.

(Middleton-Lee 2012, 6)

This difference in perspective likely arises from the different responsibilities that Member States have for international cooperation as compared with civil society. For UN Member States, the UNAIDS PCB is one venue among many within which states coordinate their activities. Collaboration across all these venues depends entirely on the goodwill and reciprocity of states. Follow through is dependent on each state’s commitment to the joint agreements. By contrast, for the NGO Delegation, the UNAIDS PCB represents a rare UN

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In December 2012, regarding Decisions 4.5, 4.6, and 4.8 of the 31<sup>st</sup> meeting of the PCB, on “Gender Sensitivity of AIDS Response” the Islamic Republic of Iran disassociated on all three decisions and the Arab Republic of Egypt disassociated on the latter two decisions.

venue within which civil society has substantial opportunities for influence. Somewhat ironically, the fact that Iran and Egypt disassociated themselves from specific decisions indicates their acknowledgment of the legitimacy of the UNAIDS' PCB decisions. The language of these decisions matters to them. Otherwise, they could simply choose not to concern themselves with the decisions.

The main tension for legitimacy for the UNAIDS PCB is between the focus on the most marginalized groups and their human rights that the NGO Delegation brings and the opposition of some governments<sup>84</sup> to making these groups and their rights a priority. The hardest balancing act for UNAIDS is between focusing on providing equal respect and concern to the groups that are most marginalized within the epidemic—the key affected populations, that are multiply-marginalized in almost every country, and women and girls overall – and maintaining the legitimacy for UNAIDS' actions, and the actions that Member States are called on to perform, that cooperation among all Member States provides.

*Dilemma 2: Subordinated groups within civil society*

Member State delegates, such as those from Iran and Egypt in 2010, 2012, or 2013, that regard the NGO Delegation as wielding too much weight in the PCB also regard subordinated groups within civil society as having plenty of access -- more than is warranted -- to the PCB. The evaluation of UNAIDS in 2012 indicated as much: "Some Member States express strong concern about what they perceive as over-representation of key affected communities in the NGO Delegation - considering it to be disproportionate and unhelpful" (Middleton-Lee, 26). Yet the evaluations in 2008 and 2012, as well as

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<sup>84</sup> Some Member States are consistently supportive of the human rights of key population groups, primarily the Nordic states, the Western European states, and the Latin American states.

contributors to a special report in the journal *Lancet*, found significant gaps in the representation of those most marginalized, particularly in terms of the participation by, and attention to the needs of, gay men and other men who have sex with men, sex workers, and people who use drugs (Das and Samarasekera 2008, Poate et al. 2009, Middleton-Lee 2012). While the authors of the Second Independent Evaluation found some progress in UNAIDS' leadership in supporting country-level services for these multiply-marginalized groups, they saw continued absence of leadership regarding the human rights of these group members, including, at times, a lack of support or urgency from country-level staff for the human rights of key populations (Poate et al. 2009).

Over time, the NGO Delegation increasingly has paid conscious attention to issues of the most subordinated groups, despite criticism for this from some Member States and others in civil society (Middleton-Lee 2012). The NGO Delegation has developed recruitment criteria to ensure better inclusion of subordinated groups, including giving preference to candidates openly living with HIV and key affected populations, with a requirement that a minimum of three delegates be living with HIV (NGO Delegation 2008). The 2012 evaluation reported that Member States and civil society largely felt that the NGO Delegation has improved in inclusion of representatives from key populations and the quality and experience of those selected to serve (Middleton-Lee 2012).

However, there are still some concerns. These include concerns that geographic representation has substantial gaps, with some areas consistently unrepresented. The clearest examples of this are in the Middle East and North Africa, part of the African region, and the Caribbean, part of the Latin American and Caribbean region. In the 20 years of the PCB, there has been one representative from the Middle East and North Africa. The

representative, Nadia Rafif of Association de Lutte Contre le Sida (ALCS), Morocco, served from 2011-2013. Similarly, until the selection of a representative from the Caribbean Network of People Living with HIV (CRN+), the Caribbean region had representation for only two years: with Robert Carr, who was replaced by Ian McNight, from the Caribbean Vulnerable Communities Coalition, Jamaica, serving in 2009 and 2010 (NGO Delegation 2014).

### *Dilemma 3: Burden*

The work burden dilemma refers to the tension that exists between the opportunity to bring voices of excluded people to decision-making bodies and the cost to individuals and their organizations as a result. This tension is particularly acute because dominant social groups do not need to volunteer their efforts in this way. Rather, they can expect their governments to protect their interests.

For the PCB work, the amount of time expected of NGO Delegates is substantial. Delegates make a commitment of ten hours per week, which equals 25% of full time work.<sup>85</sup> For the non-governmental organizations that hold the seats and support each delegate's time out of their own budgets and work plans, this equals a considerable amount of unpaid work. The work burden is a barrier to participation by smaller civil society organizations. To help the NGO Delegation participate in board work on a more equitable basis, the PCB agreed, in 2007, to provide staff support in a "Communications and Consultation Facility" (Decision 9.1 of the 20<sup>th</sup> meeting of the PCB). Even so, the NGO Delegates remain at a disadvantage as compared to Member States and the UNAIDS co-

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<sup>85</sup> Further, the 2012 evaluation found that Delegates often work more hours than this (Middleton-Lee 2012).

sponsors. The 2008 evaluation noted that the “resources available to NGOs contrast sharply with those for other delegations to the PCB – which benefit from their institutions’ considerable financial, policy and administrative support.” (Poates et al. 2009, Annex 8, para 3.49). Yet, even though participation is costly in human and financial resources, the alternative for NGOs and their delegates would be a PCB that insufficiently attends to the needs of those most affected by HIV and most marginalized in their own countries.

### ***Summary***

In summary, systems of representation that meet liberatory ideals can be developed. Indeed, current processes exist that reach toward the achievement of these ideals. Rather than evaluating representation processes as liberatory or not, it is more useful to think of these processes as falling along a continuum with different factors contributing more or less to the political equality of marginalized groups.

This chapter identified three goals and three dilemmas for a system of liberatory representation. The goals for liberatory representation are for subordinated groups to experience: equal respect and concern in decisions that affect the group; increased status for the group, as they are seen to an ever greater extent as equals in governance rather than people needing to be governed by others; and the development of new partnerships within which marginalized groups can work with other groups to identify shared interests and engage in joint strategies. The dilemmas that must be addressed are foreseeable but undesired consequences that can result from increasing the voice of marginalized groups: more conservative states may withdraw their participation from international institutions if these institutions are perceived as insufficiently state-centric; the voices of more privileged members of marginalized groups may be amplified at the expense of those with

less power or subordinated within the group; and marginalized groups may have to shoulder heavy burdens of participation, in terms of human and financial costs – burdens that would be unnecessary if they were treated with equal respect and concern by their governments.

An examination of the structures and practices of the United Nations Permanent Forum on Indigenous Issues and the Joint United Nations Programme on HIV/AIDS--two global institutions devised to bring greater voice to marginalized groups, affected by state and global decisions—demonstrates both possibilities and challenges for other organizations seeking similar goals. Both representative bodies have increased the influence of marginalized groups, Indigenous Peoples and communities of people living with and most affected by HIV, respectively. The influence is most clear, however, within the bodies themselves. It is not clear yet whether these bodies bring significant changes for marginalized group members back at home.

The formal role for the NGO Delegation as a board member within the UNAIDS PCB allows for more influence than the advisory role established for the Permanent Forum. Improvements in status can be identified for both groups as a result of their participation in these representative bodies. However, again, the status improvements have occurred within the bodies themselves, which, while important in their own right, provide little information about improvements for communities where they live.

Similarly, within the representative bodies, Indigenous participants and people living with and affected by HIV have developed partnerships across regions and with Member States. There is some evidence that these partnerships may also extend to the country level in some instances as members of the Permanent Forum and the NGO



Delegation build relationships with governments at the global level that continue at the country level. Both representative processes have established geographic criteria that assure some diversity of voices from marginalized groups. In addition, the NGO Delegation recruitment criteria, which prioritizes gender equality and applicants from the most marginalized affected groups, increases the participation of those who are subordinated within oppressed groups.

Organizations and individuals representing marginalized groups, in both bodies, take on a burden in order to get attention to their communities' needs. A few ameliorating factors have been put in place that affect these burdens. For the NGO Delegation, the PCB directed UNAIDS to fund support staff to help with administration and communication. The Permanent Forum formally meets only a few times per year, which can limit the burden for members as well. However, experience shows that concerns about human rights violations against Indigenous Peoples in countries around the world mean that Permanent Forum members can feel an almost constant responsibility to use their position to draw attention to these violations.

The institutional legitimacy of the U.N. as a state-centered body for global governance is protected in both cases by rules limiting the influence of non-state actors. This includes the advisory role of the Permanent Forum and the voting restrictions on the NGO Delegation. Even so, when the Permanent Forum or the NGO Delegation has been seen as pushing too hard for a political voice, there has been a backlash from governments that threatens to remove their consent from some of the U.N. processes (such as reduced commitments to follow through on provisions of U.N. Declarations to which they are signatories or exiting from cooperation in the U.N. consensus-system for decision making).

The more influence that a representation process allows to the people who are most subordinated domestically, the greater the challenge to the legitimacy of the process by governments.

When working within intergovernmental institutions, as experienced by both the Permanent Forum and the NGO Delegation to the UNAIDS PCB, the result is that an increase in the opportunities for a liberatory practice can perversely decrease the state support for the institution overall. Attention will be required by both civil society and supportive states to keep the right level of tension such that oppressed groups receive as much attention to their needs as possible without greatly damaging the institution in the eyes of less supportive states.

## CHAPTER 8 CONCLUSION

Previous struggles by African Americans in the U.S. South for national-level recourse for state-level discrimination provide lessons for current struggles for participation by marginalized groups. In Atlantic City, in August of 1964, the delegates to the U.S. Democratic National Convention found themselves entangled in conflict. This was not a battle over which Democratic Party presidential candidate to nominate for the general election in November, as would be typical for national party conventions. In 1964, the nomination of Lyndon Baines Johnson, already serving as President for a year since the assassination of John F. Kennedy, was secure. Indeed, Johnson would be selected as the nominee by acclamation at this Convention. Instead, the fight was about legitimate representation at the national convention for people who were denied access to the state-level nominating conventions.

The Democratic Party in the State of Mississippi had sent an all-white delegation to the Convention, following a whites-only selection process. The Mississippi Democrats had a long-standing practice of denying to African Americans any voting rights, including the right to participate in the selection of delegates to the national convention. This practice was still the order of the day in 1964 despite a U.S. Supreme Court ruling in 1944 that prohibited it.<sup>86</sup>

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<sup>86</sup> In *Smith v. Allwright*, 321 U.S. 649 (1944), the U.S. Supreme Court decided that political parties cannot be treated solely as private organizations given the near-exclusive influence they have on selecting candidates for public office. Instead, political parties are understood as partial state actors that are subject to the 14<sup>th</sup> and 15<sup>th</sup> Amendments of the U.S. Constitution. As such, political parties are not allowed to set internal rules for membership that deny voting rights based on race. This ruling, combined with subsequent local court challenges by African Americans across the South, had a noticeably positive effect on African American voter registration rates in the region. Nevertheless, voter registration rates remained low in the region and lowest of all in Mississippi, where white state and

In response to this discrimination, African Americans in Mississippi, led by Robert Moses of the Student Non-Violent Coordinating Committee and local organizers Fannie Lou Hamer, Victoria Gray, Annie Devine, Lawrence Guyot, and others, formed a new, multiracial, state Democratic Party, that they named the Mississippi Freedom Democratic Party (Branch 1998, Miller 2014). The Freedom Democratic Party held a separate nominating convention in Mississippi, where they selected sixty-eight delegates to the National Convention. These delegates drove to Atlantic City, bringing with them the burned-out skeleton of a car, a tall scorched cross leaning where the windshield had been, to show the kind of violence that was directed at those who organized African Americans to vote (Branch 1998, Freeman undated).<sup>87</sup>

Both the all-white Mississippi Democratic Party and the Mississippi Freedom Democratic Party claimed to be the legitimate party organization for sending delegates to the convention. The other state party delegations were divided in their support, with friendly delegations slipping their credentials to members of the Freedom Democratic Party to get them access to the meeting hall.<sup>88</sup> The controversy angered Johnson, who had been strategizing behind the scenes to keep civil rights activists quiet for the duration of

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local officials made disenfranchisement of African Americans a point of honor (Klarman 2001). In March of 1965, only 6.7% of eligible African American voters in Mississippi were registered to vote (Grofman et al. 1992, 23-24).

<sup>87</sup> Branch (1998, 457) describes this car as a replica of the one belonging to Michael Schwerner, the young civil rights worker from New York who was murdered along with fellow civil rights workers James Chaney, from Mississippi, and Andrew Goodman, also from New York, during the Mississippi Freedom Summer in 1964. Freeman (undated) provides photos of the car brought to Atlantic City and placed outside the convention center.

<sup>88</sup> The Mississippi Freedom Democratic Party documented support from the State Democratic Parties in California, Massachusetts, Michigan, Minnesota, New York, Oregon, and Wisconsin, as well as Denver and Adams Counties in Colorado in the challenge that they presented to the National Democratic Party Credentials Committee (Mississippi Freedom Democratic Party 1964).

the Convention, to keep the white Southern Democrats within the party fold, and to have a positive forward-looking Convention that demonstrated strong support for his nomination (Branch 1998).

The Credentials Committee held formal hearings with the members of the traditional Mississippi Democratic Party and those from the Mississippi Freedom Democratic Party. The Freedom Democrats offered a compromise that had been adopted previously when two competing delegations came from the same state: to split the seats evenly between the traditional party delegates and the Freedom Democrats' delegates (Miller 2014). Instead, the Credentials Committee offered a different compromise: the traditional party members would keep their seats as long as they signed a loyalty pledge to support the Democratic convention presidential nominee in the general election and the Freedom Democratic Party members would get two at-large seats at the Convention, although they would not be allowed to select who in their group would hold those seats (Branch 1998).<sup>89</sup> Johnson, Hubert Humphrey (Johnson's choice for his vice-presidential running mate), and national male civil rights leaders, including Dr. Martin Luther King, Jr. and Joe Rauh, the Freedom Democrats' lawyer, and United Auto Workers Union President, Walter Reuther, supported the compromise and urged the Freedom Democrats to agree (described by former Vice-President Walter Mondale, a member of the 1964 Credentials

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<sup>89</sup> Specifically, Johnson insisted that Fannie Lou Hamer not be selected as one of the two delegates from the Freedom Party. Hamer had provided powerful and gripping testimony during the Credential Committee hearings about the beatings and death threats she and others had endured in order to register to vote. Mondale described her testimony as, "so effective that Lyndon Johnson held a news conference to try to take the television cameras away from her testimony" (Ginther 2014, 108). In negotiations over the proposed compromise, Humphrey stated to Robert Moses, Dr. King, and Bayard Rustin, that, "the President will not allow that illiterate woman to speak from the floor of the convention" (Branch, 1998, 470).

Committee, in an interview with Ginther (2014), 109). In deliberations with the Freedom Democrats and civil rights activists about the compromise, Robert Moses argued against the compromise on principle, saying, “We’re not here to bring politics to our morality but to bring morality to our politics” (Branch 1989, 474). In the end, the women and men of the Freedom Democratic Party rejected the compromise, with Fannie Lou Hamer’s famous assertion, “we didn’t come all this way for no two seats” (Branch 1989, 474). When the Freedom Democrats refused the compromise, the National Democratic Party voted to seat the all-white Mississippi Democrats and exclude the Freedom Democrats from the Convention (Bracey 2011, 119).

Fifty years after the convention, many critiques can be found. Lytle (2006) describes the Freedom Democrats as “outmaneuvered in the end,” arguing that Johnson was able to gain the perception of unity at the Convention that he so much desired (162). Mark Miller (2014) was the SNCC regional representative charged with gaining the support of the California Delegation for the Freedom Democrats. He questions, in retrospect, the decision not to take the two seats that were offered because of the subsequent retaliation by the National Democratic Party. As Mississippi began to democratize under the Civil Rights Act (1964) and Voting Rights Act (1965), the Johnson and the National Democratic Party made sure that funding and support went to Mississippi Democrats not affiliated with the Freedom Democrats (Miller 2014, 16). Mondale highlights the symbolic aspect of the proposed compromise, explaining in a 2014 interview, “what we did was that we came up with this idea of seating, two delegates, one white, one black, which would be the first black delegate from Mississippi as a matter of symbolism” (quoted in Ginther 2014, 110). However, members of Freedom Democratic Party continue to express support for their

decision, seeing themselves as holding in trust the wishes of the people in Mississippi who voted for them. In 1985, Victoria Gray Adams explained, once again, the decision to reject the compromise. Her language focuses on participation as a fundamental right:

You know for those who are unable to understand why we were unable to accept that compromise...what they didn't realize was we would have been betraying those very many people back there in Mississippi whom we represented, who not only had laid their lives on the line but many who had, who had given their lives in order for this particular event to happen... [Y]ou know we realized that we came with nothing, and it made no sense at all with all the risk that had been taken...to accept what we knew for certain to be nothing, and to go back [to Mississippi] to God only knows what. And I doubt if there was a person in that delegation that did not realize that. You may get home and not have a house. You may get home and a member of your family might be missing, or you may not get home at all. And so, you know, we are not going to accept anything less than what we came after, which is the real thing, which is representation, which is the right to participate, and if we don't get that then we'll go back and take our chances and regroup and come to fight another day. And that is precisely what we did.

(Interview with Victoria Gray Adams 1985, camera roll 345).

Relevant lessons can be drawn for a theory of liberatory representation from this episode in the U.S. civil rights movement. First among these is that the advantages of traditional electoral processes may be overstated in terms of their abilities to provide representatives that truly represent the diversity of people within their boundaries. Instead of treating any deviations from geographic-based electoral districts as regrettable, lesser forms of authorization and accountability, this demonstrates that multiple forms of representation are often needed, no matter what the underlying system, to protect oppressed groups' right to meaningfully participate. Until the Voting Rights Act of 1965, and federal marshals, put an end to race-based exclusion at Mississippi's voting booths, African Americans in Mississippi were considered legitimately represented by Representatives elected in all-white elections. Even after discrimination was outlawed, their photographs continue to hang on the walls and their names continue to be recognized

in history books. Ideas about the legitimacy and proper selection of representatives are not, and have never been, set in stone. They change over time. Equally important, the idea that the highest and clearest form of legitimate representation occurs when there is a process of formal authorization and accountability expressed through voting by constituents within clear geographic boundaries fails to hold up under scrutiny. There is a need for meaningful processes of representation that ensure a political voice for those who are persistently and perniciously excluded from decision-making processes that affect them.

The experience of the Freedom Democrats provides a further lesson: that physical presence for historically excluded groups matters. As Phillips (1995) has argued, the idea that one either represents ideas or people is a false dichotomy. Instead, these are fundamentally linked. Indeed, it became clear in Atlantic City that even national-level civil rights leaders, who had similar overall goals as the Mississippi Freedom Democrats, could not speak for the concerns of the sharecroppers, farmers, and laborers who came from Mississippi, who were elected to represent the African American and progressive white people of Mississippi, and who would return after the convention to conditions of violence and intimidation in Mississippi. The national civil rights leaders could agree to a negotiated compromise that left the all-white Mississippi delegation holding all of the seats reserved for Mississippi; the Freedom Democrats could not.

One final lesson is illustrated by the struggle at the Democratic National Convention: there is more at stake in a representation process than any individual outcome. In fact, there is more at stake than the outcomes at all. What is important is not simply that the ideas and preferences of marginalized groups be represented – indeed, given the clear support for Johnson’s nomination, the preferences across groups were already known – but



that equal status and respect be accorded to those groups that are oppressed by others, yet are clearly part of the whole. While the outcome of the convention was established in advance, what was not established was the extent to which basic civil rights of marginalized groups would be recognized, particularly when it was not politically expedient. For the Democratic National Convention in 1964, what was at stake was the call for equality, respect, and concern. The Freedom Democrats, through bringing their challenge and through refusing the compromise that was offered, demonstrated their commitment that African Americans, even in the most racist areas of the U.S. South, should be able to live lives with the greatest physical well-being, development of their capacities, and social dignity possible. They refused to drop their insistence, even when their arguments were unsuccessful, that they be recognized as equal members of the shared political community created within the convention.

The efforts by the Freedom Democrats highlight the reasons why elites who are not part of the group cannot ultimately provide the benefits of representation that groups need. For example, Bono, from the Irish rock band U2, has used his celebrity status to bring attention to the needs of Africans affected by HIV. He has framed his efforts in terms of self-authorized representation (as quoted in Iley 2005, 22):

I represent a lot of people who have no voice at all. In the world's order of things, they are the people that count least. They are the 6,500 people who are dying of Aids in Africa every day for no good reason. They haven't asked me to represent them. It's cheeky but I hope they're glad I do.

What Bono has been able to do is to bring attention that they might not get otherwise to those who are severely marginalized and, to some extent, to convince conservative U.S. lawmakers and leaders to care about Africans living in poverty and affected by HIV (Adam

2013). However, a point of clarity is required for his claim: he does not speak *for* people, he speaks *about* people. The difference is critical for any theory of representation. The representation claim made by Bono highlights a critical concern for political representation: who does one speak for and who does one simply speak about? For people who are marginalized, this is the difference between their agency and their objectification. Gaining the attention and concern of leaders and celebrities may be a step forward from invisibility and neglect, yet it comes with serious dangers. Among these dangers are the chance that stereotypes will be reinforced that the group is incapable of speaking for itself and needs the guardianship of elites and that self-appointed spokespeople will be wrong about what the group members really need.

The questions raised by the Mississippi Freedom Democrats' challenge to the 1964 Democratic National Convention go to the old question of whether subordinated groups seeking freedom from domination should focus on changing hearts and minds or on changing laws and policies -- and claims both. These goals can be achieved through inclusive representation, skilfully constructed and deliberately implemented and maintained. This project provides a framework for an inclusive and liberatory system of representation, centred on three goals to be achieved and three tensions to be addressed. The next section provides a summary of the arguments for more inclusive representation processes and the proposed framework for liberatory representation.

### ***A look back at where we have been***

This project has focused on a specific democratic challenge: the meaningful participation in decision-making by the people who are most affected by the decisions made yet have the least influence on the shape that those decisions take. Certainly, political

decisions have different effects for different groups. One of the primary purposes for the existence of political processes is precisely to determine a just distribution of the costs and benefits that arise within a political community. Yet, if democracy is going to have any substantive grounds, as I have argued here that it must, than it cannot mean that some people are persistently and arbitrarily denied the right to effectively shape the conditions under which they live. Without processes of inclusive representation that ensure the meaningful participation of marginalized affected people in decision-making, then marginalized people are pushed into the role of wards of the more dominant social groups. That is, people who are capable of self-governance and equal in human rights to their neighbors within a political community are treated, because of biases based on who they are, as political children for whom decisions – including those designed to regulate their behavior and to impose material and other costs -- are made by others. This project seeks to address this problem within one level of governance: that which takes place within global institutions.

With inclusive representation supported, in principle, further democratic concerns arise. Three sets of concerns about inclusive representation can be identified: whether amplifying the voice of marginalized people violates the equal participation rights of majorities; whether increasing the influence of marginalized people similarly harms majorities; and whether a principled set of criteria to determine which communities should, or should not, be included in a given decision-making process can be established. When these questions are explored at the level of global governance, they can be distilled into questions of the proper relationships between marginalized groups, affected by

particular decisions or decision-making bodies, and the governments who are the formal representatives of their states and populations within global fora.

Concerns about the potential loss of influence for dominant groups often fail to account for these groups' overrepresentation within domestic decision-making processes. By contrast, groups with low social status -- those subject to the relations of the ban -- watch as the agendas of their governments, the topics for discussion, and the decisions taken pass them by. Dominant groups use the apparatus of the state to ensure that their needs are met and that the costs incurred by the political community are largely passed on to others. Amplifying the voices of oppressed groups has the effect of increasing group members' access to government attention, discussion agendas, and recourse for harms inflicted on them by state or individual actors. Further, including the voices of those otherwise excluded provides the full information about the experiences and interests of all groups that is needed for good democratic decisions to be made.

However, if opportunities are created to amplify the voices of marginalized groups, but there are no protections for their influence, then the processes are likely to deteriorate into tokenism. If it is important that oppressed people speak, then it is equally crucial that their words will matter. Without ensuring influence, then the democratic and political "goods" created by increasing the voice of marginalized groups will not be sustained. The participation of members of marginalized groups is required to equalizing access to state attention and to bring forward fuller information about decisions to be made; if this participation turns out to make no difference in the lives of the groups that are supposed to benefit, then there is no reason for them to continue to participate. Indeed, the two groups examined in these chapters, Indigenous Peoples and people living with HIV, have

consciously organized themselves in response to exclusion at the state level. These groups seek, to use Dworkin's language, "procedures that protect and respect" the democratic conditions of "equal status for all." Without such procedures, global decisions simply reinforce domestic inequalities.

Inclusive processes for decision-making create the possibility for equal status for dominant and marginalized groups. There remain other challenges, however, including questions of practically determining which groups to include. Building on close attention to issues of representation and domination described by Held (2003), Young (1989), and Mansbridge (1999), six criteria can be identified to address this challenge. The purpose for inclusive representation is not to include everyone who is interested in a given issue but, rather, to ensure that those who have been most affected, but least able to affect, decisions are able to participate in the decision-making process. For the following criteria, the greater the extent to which a group meets these criteria, the stronger the case for inclusion in the decision-making process:

- 1) The members of the group will have their life expectancy or life chances affected by the decisions to be made.
- 2) The group is situated differently from other groups such that its experiences and understandings of the issues at hand are unlikely to be included in deliberations.
- 3) The group's interests are unlikely to be meaningfully included in decision-making without specific representation.
- 4) Group members have a history of distrust of political leaders, such that they will not expect the existing decision-making bodies to take their concerns into consideration equally with the concerns of others.
- 5) Group members have been, or continue to be, viewed by dominant groups as incapable of meaningful participation as political equals.
- 6) The decision-making body will address new or emerging issues which affected groups will not have had prior opportunity to discuss and determine their positions.

Using these criteria, any decision-making body can identify groups that are significantly affected and likely to be disregarded without representation. Further, groups that find

themselves excluded from decisions that affect them can use these criteria to petition for entry into the decision-making body.

Taken together, the arguments for inclusion of representatives of marginalized groups and ensuring their influence on outcomes and the criteria for determining when a particular group ought to be at the decision-making tables, provide a rationale and a structure for processes of inclusive representation. Treating members of marginalized groups as equals, with the ability to represent their own community interests, creates the conditions under which equal status can be realized. This is the reason that Young (1989, 262) has argued for inclusive representation, because of its potential “to undermine oppression” that excluded groups otherwise experience. To this basic structure, further attention to the goals and challenges of representation is needed.

Questions about political representation go to the heart of every democratic process that is not based on direct democracy. As such, contemporary political theorists have devoted significant normative and empirical attention to questions of substantive representation, minority influence, tokenism, deliberation quality, and status among representatives. These efforts contribute to this project’s focus on liberatory processes of representation within global institutions for marginalized groups. Representation that meaningfully includes oppressed groups within decision-making bodies is anticipated to offer many democratic benefits. The increase in information and additional approaches to problems is expected to lead to better decisions. With a greater diversity of experience in the room, the quality of deliberations should improve, leading to better outcomes. Further, including members of marginalized groups as part of the decision-making body demonstrates their political equality as full partners in responding to joint problems and

shared concerns. This is expected to result in increased status, thus reduced marginalization, for members of these groups. Finally, more inclusive representation increases the democratic accountability of the institution through ensuring that greater numbers of communities that are affected by the institution's activities are able to track, monitor, and communicate policies and their effects.

However, inclusive representation may also lead to outcomes that are not liberatory for marginalized groups. Existing hierarchies of power and status pose critical obstacles. If these hierarchies are reinforced, rather than dismantled, through the process for representation then the democratic possibilities will not be realized. Members of previously excluded groups may be welcomed into decision-making bodies, within which the existing power hierarchies that oppress them remain unaddressed. When this happens, marginalized groups will continue to lack influence in the decisions that affect them. Even if the representatives from marginalized groups are recognized as equal partners within the decision-making body, concerns about unjust status hierarchies remain. When representation processes are designed as if all members of marginalized groups are similar in interests and in needs and are similarly placed in terms of power, the result is a further reinforcement of existing hierarchies within the group. Those who may be subordinated within the group already, because of their gender, race, sexual orientation, or some other characteristic, thus become further silenced and invisible.

Another challenge that proponents of inclusive representation processes must address is the way that structural violence, experienced by marginalized groups, affects their participation in decision-making. From discrimination in the legal environment, such as laws criminalizing gay men, lesbians, and transgender people or enhanced police

surveillance in racial minority or immigrant communities, to the financial, emotional, and psychological costs of participation, marginalized groups face different and harsher obstacles to participation when compared with dominant groups. This structural violence that leads to a disproportionate burden for marginalized groups seeking participation in decision-making.

Further adding to the list of obstacles, those who seek more inclusive global decision-making processes must contend with a state-centric global system that is structurally rigid when it comes to civil society influence. Marginalized peoples face conflicts between legitimizing the existing global hierarchies and seeking to strengthen multilateral organizations, while simultaneously seeking greater autonomy and rights of participation in governance. Protection of state sovereignty, particularly for poorer and weaker states, is critical to ensure global stability and provide a shield against domination by stronger states, as argued by Roth (2011). This stability protects both dominant and oppressed groups, although the benefits disproportionately flow to the elites. However, there is a price paid for a global architecture founded on state power and that price is largely paid by marginalized racial, ethnic, and sexual minority groups within the state. Currently, international institutions seek to maintain the existing architecture, states seek the greatest legitimacy possible to pursue their interests, and members of marginalized groups to attempt to shift the balance of power, however slightly, in their direction.

There is a delicate balancing act taking place between the powers of the state, global institutions, multinational corporations and business interests, and NGOs and civil society organizations. From the position of marginalized groups, the state, which holds the responsibility to protect citizen rights, frequently uses its power to ignore or actively



oppress racial, ethnic, and sexual minorities; global institutions sometimes wield moral authority in their favor, but their foundation in the states means that they offer constricted support in practice; multinational corporations and business interests largely serve to minimize the space within which states, global institutions, and civil society can maneuver, working to ensure their own access to natural resources, intellectual property, and the highest prices that they can force markets to accept. Determining the entry points for action is difficult: states consistently prove uninterested in the human rights of marginalized groups within their borders. Corporations may offer token opportunities for individual participation but will not support efforts to redistribute power and resources in the ways needed to reduce competition within and among states for resources and provide economic security to marginalized groups. If global institutions provide more power and meaningful voice to marginalized groups, or any sections of civil society, they risk losing the support of states, and, thus, their legitimacy to do anything at all.

In this project, I have presented an approach for achieving the rewards and managing the risks of inclusive representation that global institutions and members of marginalized groups alike might adopt. The framework for liberatory representation provides a means for institutionalizing processes that are focused on removing domination and meaningfully increasing respect and concern within the lived experiences of marginalized groups on issues that substantively affect them. The framework is based on the commitment to three goals: 1) representatives of marginalized groups must be able to influence the outcomes of decision-making processes; 2) improved status for the marginalized group such that they are able to experience equal respect and concern in decision-making; and 3) the development of partnerships between marginalized groups

and others in the decision-making body, through greater understanding, mutual education, and the identification of issues of shared concern. In addition to the three goals, this project has argued that there are three crucial dilemmas to which liberatory representation processes within global institutions must attend. The first is that the processes must seek to protect the legitimacy of international institutions, recognizing that marginalized people are better protected when states support international institutions than when they do not. The second requires that representation processes for marginalized groups, while protecting the rights of group members in general to select their representatives, are structured such that group members who are subordinated within the group are also able to bring forward their concerns and experiences as part of the decision-making body. The final dilemma draws attention to the burden born by representations who are part of marginalized groups – burdens that can relate to discrimination or isolation within the decision-making body, to processes set up for the comfort of dominant group members (such as operating procedures, timing of breaks, types of food served, and payment and reimbursement processes), and to the larger system of structural violence within which they and their constituents live and work. The dilemma is to create processes of meaningful inclusion that recognize and seek to level the effects of the unequal burdens carried by representatives from oppressed groups.

***A look forward to where we are going***

The liberatory framework for representation sketched in this project calls for representation for marginalized groups so that marginalized groups can enjoy liberal democratic values of autonomy, personal development, and freedom from domination. The framework requires specific actions on the part of more dominant groups to make this

happen: these include making space within the decision making body for those who are at the intersection of multiple marginalized identities; and attending to, and working to ameliorate, undue burdens placed on representatives from marginalized groups in order to participate. A central challenge for this entire project is determining how and why current elites would agree to share power, however slightly, and to extend their efforts in this way. The arguments made in the language of liberal democracy are unlikely to persuade those who benefit from the current system and who, by virtue of their status, are able to ignore or rationalize the plight of those who are oppressed. This project described two examples of groups, Indigenous Peoples and people living with HIV, who combined pressure with language – language that was adopted initially in small ways, by few U.N. Member States -- to successfully gain formal rights of participation in decision-making within the U.N. system. Is this the process for other groups to follow? What kinds and levels of pressure from marginalized groups; what language of democracy, liberalism, human rights, or efficiency; what calls to the self-interest of elites are able to speak to dominant groups and allow the development of these kinds of processes?

Further research should examine the question of influence within decision-making bodies. Specifically, researchers can observe interactions within meeting: who speaks; who is responded to or noted in responses by others at the table; who is involved in conversations behind the scenes? These questions need to be studied over an extended time period because silence can be a strategy at any particular meeting and changes may be seen over time. The critical analysis to follow from these studies and observations is to determine what outcomes can be traced to the influence of representatives from marginalized groups at the meeting.

Research questions on status also call out for further attention. To what extent does inclusion in decision-making bodies, as theorized, improve the status of groups? Researchers can explore whether or not there are changes in perception, by members of dominant or marginalized groups, such that those who have been marginalized are now seen as partners in the mutual project of governance. If inclusion does lead to status changes, what are the mechanisms that account for this? Allport's (1954) contact hypothesis would suggest that working together to solve shared problems would break down biases against the marginalized group. Alternately, members of dominant groups could seek to be seen as on the right sides of norms they perceive as changing or could find it strategically useful to align with the representatives of marginalized groups. Also critical for understanding status changes would be to determine whether these changes are limited to the people in the room or whether the higher regard is extended more broadly: from members of dominant groups who are not part of the decision-making body and to members of marginalized groups who are also not part of the decision-making body.

There are some specific questions that marginalized groups need answered in order to plan their advocacy work. Chief among these are questions about the effects that global decisions have on the life chances of affected populations. Specifically, are decisions that are weakly worded, but that gain consensus among Member States, more likely to be implemented than more strongly-worded decisions from which Member States disassociate themselves? Do more conservative states (which can be defined depending on the issue) affirmatively implement any decisions to which they agree in global fora? Further, for social movements focused on increasing respect and concern for oppressed groups, research questions include: under what conditions is an outside strategy – of

protest or direct action -- more effective, compared to an inside strategy, or a combination? Are there claims that do not get, or seemingly cannot be, made in the representation setting that need to be made?

A concluding remark is needed here about the limits of any categories for measuring processes that affect the dignity of subordinated groups. It is clear that the inclusion of marginalized people in governance groups is greater than the sum of its parts; greater than its relative success at influence, status, and partnership; greater than its ability to solve serious dilemmas related to the role of states in intergovernmental decision-making, double and triple minorities, or burdens on groups to participate. What each system of representation creates, at the most basic level, is the chance for people who systematically are denied care and concern by states to be seen by those who are otherwise able to operate as if they do not, or should not, exist. These processes ensure for marginalized people the invaluable opportunity to sit across from government delegations and know that governments will still persecute marginalized groups, yet, these governments must, if only once or twice per year, face the members of the groups they persecute, look in their faces, and hear their assertions that they do exist, they are human, and they know that they are deserving of human rights.

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**ABSTRACT****INCLUSIVE REPRESENTATION IN GLOBAL DECISION-MAKING PROCESSES:  
CHALLENGES OF DEMOCRACY, SOVEREIGNTY, AND LIBERATORY POLITICS FOR  
MARGINALIZED GROUPS**

by

**LAUREL SPRAGUE**

May 2015

**Advisor:** Dr. Brad Roth**Major:** Political Science**Degree:** Doctor of Philosophy

This project proposes a framework for liberatory representation that institutionalizes processes to remove domination and meaningfully increasing respect and concern toward marginalized groups on issues that substantively affect them. It argues that decision-making processes that do not offer meaningful influence to those people who are most affected by particular decisions turn those who are supposed to be political equals into wards of dominant groups; essentially turning adults into political children. To meet ideals of political equality, liberatory processes for inclusive decision-making are required. The concept of political adulthood provides the foundation for an examination of current processes designed to bring the voices of affected communities into the governance of global organizations. Dworkin's arguments for "equal respect and concern" and full membership, or "moral membership," in the political community, as the essential democratic conditions provide a theoretical foundation for analysis. Throughout, close attention is paid to the political organizing work of two marginalized groups who have successfully achieved formal representation within specific U.N. bodies: Indigenous

Peoples and people living with and affected by HIV. I argue that meaningful democratic decision-making can exist outside of both legislative and geographical boundaries, but only under particular conditions of inclusion and practice. Building on the work of Mansbridge, Williams, and Young, I argue first that we need to clearly understand – in each instance – who the affected groups are that require a decision-making voice. Next, following Agamben’s “relations of the ban;” Gramscian understandings of civil society power dynamics; and Mouffe and Laclau’s work on agonistic democracy; I argue that understanding civil society processes as *politics*, that is, as spaces for contention characterized by power challenges, is essential for crafting liberatory democratic practices that meaningfully involve the needs and perspectives of those most marginalized. Finally, I offer a framework for processes of liberatory representation within global institutions. I argue that critical democratic conditions that ensure meaningful influence on outcomes, increased status for oppressed groups, and opportunities to develop perceived communities of shared fate across marginalized and dominant groups must be met. Difficult challenges, some specific to the global sphere, must be addressed: the balance of power between states and global institutions that limits maneuverability for marginalized groups; structural violence; and ensuring that those subordinated within oppressed groups are meaningfully represented.

### **AUTOBIOGRAPHICAL STATEMENT**

My work is focused on democratic processes that ensure meaningful influence by marginalized peoples within civil society and global institutions. I am most interested in the resilience and resistance of social groups when faced with stigma and discrimination and human rights abuses. In my research, I seek to close the gap between communities, and their information and analysis needs, and the academy, where resources that could actuate that research are held. Frustration expressed by non-governmental organizations (NGOs), networks of marginalized people, and global organizations, led to my dissertation research on global representation processes for oppressed groups. Since 2009, I have provided research support to a UN-civil society project: the People Living with HIV Stigma Index. The experience of providing technical assistance to communities across sub-Saharan Africa and Central/Eastern Europe has taught me to respect and learn from communities' capacity for rigorous and thoughtful research. My recent participatory research projects include: survey research on attitudes about HIV-specific criminal penalties (U.S.); structured interviews on the health, social, and political effects of HIV-related stigma (Detroit, Baton Rouge, and Vancouver); and focus groups and a survey to identify political, economic, and social needs conducted jointly with transgender people living with HIV (U.S.). I have led or supported research projects in the U.S., Canada, Central and Eastern Europe and Central Asia (five countries), and Sub-Saharan Africa (three countries). Funding for these initiatives has come primarily from philanthropic organizations in Europe and the U.S., with some travel and meeting support from the U.S. National Institutes for Health. I serve on two UN working groups to develop global HIV stigma indicators: Global AIDS Response Progress Reporting and the Indicator Working Group for the UN Monitoring and Evaluation Reference Group.