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**#2016-022**

**Public policy and mental health:  
What we can learn from the HIV movement**  
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**UNU-MERIT Working Papers**

**ISSN 1871-9872**

**Maastricht Economic and social Research Institute on Innovation and Technology  
UNU-MERIT**

**Maastricht Graduate School of Governance  
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# Public Policy and Mental Health: What we can learn from the HIV Movement

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**Keywords:** mental health, health, public policy, social mobilisation, social exclusion, poverty, HIV  
movement, AIDS, HIV, development, stigma, discrimination, social networks

JEL Code: I11, I12, I14, I15, I18, I30, O10, O19, O20

## **Abstract**

Mental health plays a key role in human development, both as a driver and as a goal in itself. Despite this, mental health has been strikingly neglected to date. The HIV movement has revolutionised health advocacy and registered remarkable successes in the past decades. The present study draws on the experience of this exceptional movement in order to find ways forward in the field of mental health. Adopting a broad analytical perspective, it discusses the differences and similarities between the fields of HIV and mental health and, based on this analysis, provides a concrete model for action that takes into account the peculiarities of mental health as a policy issue.

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# 1 Introduction

As public health issues, the Human Immunodeficiency Virus (HIV) epidemic and mental health share an all too common fate. Just as HIV when it first broke out, most mental disorders are still poorly understood and surrounded by an air of myth, superstition and prejudice. In both cases, stigma, discrimination and social exclusion play an ever important role in worsening the diseases' impact and hindering an effective response.

The HIV movement has come a long way since the first recognition of the Acquired Immune Deficiency Syndrome (AIDS) in the early 1980s. Thanks to an incessant concerted effort, HIV is nowadays a priority public health issue on the international agenda, drawing on substantial funding and strong political advocacy. Mental health, however, still remains a strikingly neglected issue, especially in low- and middle-income countries (LMICs). While neuropsychiatric disorders are estimated to account for 13% of the global burden of disease in terms of Disability Adjusted Life Years (DALYs)<sup>1</sup>, the global median percentage of government health budget expenditures dedicated to mental health amounts to a mere 2.8% (World Health Organization [WHO], 2011). Moreover, with 0.5% and 5.1% respectively, the gap between low- and high-income countries is far from proportional.

Given this setting, the overall aim of this research is to draw on the experience of the HIV movement in order to provide relevant insights on how to move mental health forward on the development agenda. Specifically, the objectives are to:

1. Explore the role of mental health in global development and identify the most relevant response gaps.
2. Discuss the key aspects that shaped the HIV movement's history and the current global response.
3. Apply the HIV movement's experience to the field of mental health and formulate concrete policy recommendations.

Even though the HIV movement is one of the most prominent global health movements, systematic analysis of its achievements has emerged only recently and remains scarce. Most notably, Kapstein and Busby (2013) provided one of the first efforts to systematically process the HIV movement's experience in order to learn for other policy areas. Similarly, despite mental health receiving increasing attention in global development, there is very few and only very recent literature aimed at systematically conceptualizing it as a policy issue. In both fields, stigma is mentioned as a major issue throughout the literature, but the application of conceptual frameworks to properly understand stigma and its etiology is still lagging behind, especially when it comes to engendering practical, change-oriented implications.

Overall, a lot of literature has been sprouting recently regarding the different elements required to answer the above research question. The present study aims to connect these elements through an extensive literature review in order to provide new insights and concrete policy recommendations.

## 2 Background

Mental health plays a key role in human development, both as a driver and as a goal in itself. People with mental disorders frequently experience severe human rights violations and are subject to social exclusion

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<sup>1</sup> Note that the WHO (2011) uses the term “neuropsychiatric disorders” and does not specify which health conditions are included. Furthermore, the figures are based on less recent data from 2004. This explains the discrepancy with the calculations by the authors for “mental disorders” (10%) introduced further on, which are based on the most recent burden of disease data and include a specific set of disorders relevant to this study, only two of which are categorised as neurological disorders in the data sets (“Alzheimer’s disease and other dementias” and “epilepsy”). In order to ensure consistency when bringing burden of disease and expenditure face to face, the figure for “neuropsychiatric disorders” reported in the relevant WHO document (13%) is used in this specific context, while otherwise the calculations by the authors referring to “mental disorders” are used.

and deprivation. Communities and governments often deny them the opportunities to reach their potential for personal well-being as well as for societal and economic participation. As the WHO (2010b) points out, people suffering from mental disorders are not only a vulnerable group by themselves, but there are also critical overlaps with other recognised vulnerable groups, where prevalence of mental disorders tends to be saliently high.

## 2.1 Mental health and human rights

People with mental disorders are especially vulnerable to experiencing human rights violations. These violations often surface in the form of horrendous stories of abuse, neglect and maltreatment of people with mental disorders in psychiatric institutions. Behind these appalling stories lies a profound structural disregard of the human rights of people with mental disorders that manifests itself on many different levels and goes way beyond the confinements of mental institutions. Besides being exposed to high levels of physical, mental and sexual abuse, people with mental disorders are often deprived of their most basic civil, cultural, economic, political and social rights (Blais, Massicotte and Yoshinaka, 2001; Drew et al., 2011). Stigma, discrimination and the lack of effective treatment and support tend to impede employment and trap people in a downward spiral of social exclusion and a worsening health condition.

In most LMICs, children and adolescents with mental disorders face disproportionately high barriers to access inclusive education or, even worse, “are institutionalized in facilities that do not offer any kind of education” (Drew et al., 2011, p. 1667). This is especially fateful because education is not only a fundamental building block for human development at large, but also plays a very specific role in the effective realisation of human rights. As Vijayalakshmi, Ramachandra, Reddemma, and Math (2013) point out, “[l]iteracy has been recognized not only as a right in itself but also as a mechanism for the pursuit of other human rights. Literacy enables a person to (...) demand protection and to make their own decisions” (p. 352).

Another important source of human rights violations is the fact that very frequently the judicial system serves as a buffer for the lack and/or inadequacy of mental health services (Mfoafo-M'Carthy & Huls, 2014). The Treatment Advocacy Center (2014) estimates that in the United States alone, there are 350.000 people with mental disorders behind bars, which is ten times the number of patients in state psychiatric hospitals. The same report, which describes prisons as “America’s new asylums” (p. 6), states that people with mental disorders are “vulnerable and often abused while incarcerated. Untreated, their psychiatric illness often gets worse, and they leave prison or jail sicker than when they entered” (p. 6).

## 2.2 Health impact

The global burden of disease of mental disorders<sup>2</sup> is estimated at 10% in terms of DALYs and at 28.2% in terms of Years Lived with Disability (YLDs) (WHO, 2014). With 6.2%, the proportional impact measured in DALYs is considerably smaller in low-income countries, mostly due to the high prevalence of fatal communicable diseases. When measured in YLDs, at 25%, the burden of disease in low-income countries approaches the global average. Even though these figures are already substantial, the actual health impact of mental disorders extends way beyond these calculations.

First, mental disorders often go undiagnosed or even unrecognised due to a lack of adequate mental health services and/or low health literacy. Even when diagnosed, stigma frequently leads to considerable underreporting (WHO, 2010a). The scope of this underreporting is difficult to measure and varies according to each specific setting, but, as a study by Takayanagi et al. (2014) indicates, it might be even larger than often assumed. The researchers asked participants of the longitudinal Baltimore Epidemiologic Catchment

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<sup>2</sup> Note that all figures referring to “mental disorders” are calculations by the authors based on the most recent data from 2010-2012 (WHO, 2014) (compare *Footnote 1*). Included health conditions are: (a) mental and behavioural disorders: all; (b) neurological health conditions: Alzheimer's disease, other dementias and epilepsy; (c) self-inflicted injuries;

Area Survey about previous mental disorders. The discrepancy between the answers provided by participants and actual mental health history was striking: major depressive disorder: 4.5% vs. 13.1% / Obsessive-compulsive disorder: 0.6% vs. 7.1% / Panic disorder: 2.5% vs. 6.7% / Social phobia: 12.6% vs. 25.3% / Alcohol abuse or dependence: 9.1% vs. 25.9% / Drug abuse or dependence: 6.7% vs. 17.6%.

Second, mental health has a profound impact on physical health that is not reflected in official statistics. For example, mental disorders significantly increase the risk of developing serious physical health conditions like diabetes, heart disease, stroke and respiratory disease (Prince et al., 2007; WHO, 2010b). Additionally, mental disorders have the potential to significantly increase the impact of otherwise independent physical disorders. For example, a study by Cook et al. (2004) found a more than doubled mortality in women living with HIV and depression as compared to women living with HIV alone. The causal pathways depend on the specific disorder and are so complex and manifold that quantifications are usually bound to the very specific setting in which they have been carried out. This complete statistical separation between mental disorders and their disabling and fatal physical consequences might explain to a large extent why the relative burden of disease of these health conditions is so much lower when measured in DALYs, which include the years of life lost, than when measured in YLDs. In addition to these connections between physical and mental health, the above mentioned human rights violations against people living with mental disorders have their own effect on physical health and mortality. For example, the WHO (2010b) reports a case from Indonesia where 291 out of 644 residents (45%) in Jakarta's four psychiatric institutions died from diarrhoea and malnutrition between 2007 and 2009.

### **2.3 Mental health and development: a negative cycle**

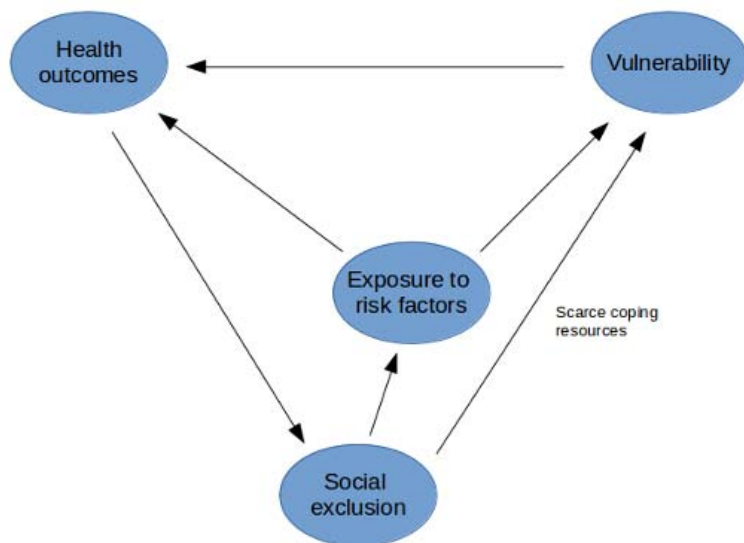
The etiology of mental disorders involves a complex interaction of genetic, other biological, psychological and social factors. The fact that the incidence, prevalence and especially the course of disorder vary substantially according to social settings suggests that social determinants play an important role (WHO, 2010a). There are consistent patterns that connect factors associated with poverty and social exclusion with the triggering and progress of different mental disorders. For example, when analysing the differential exposure to risk factors for unipolar depression, the WHO (2010a) came to the conclusion that all the exposures were overrepresented in poor communities. The factors involved include civil unrest, social conflict and exclusion, obstetric risks, lower socioeconomic position, violence, natural disasters, working environment, lack of social capital, exposure to toxins and many others. The same report also found substantial differentials in vulnerability, i.e., the ability to cope with these exposures. People suffering from social exclusion and poverty tend to have decreased health literacy as well as limited access to treatment and support. Besides this vulnerability in terms of scarce coping resources, there is also an independent effect of exposure to risk factors at one point in life on future medical vulnerability. For example, it is well established that early life stress (e.g. childhood abuse or neglect) constitutes a major risk factor for developing depressive disorders later in life through gene-environment interactions and epigenetic mechanisms (Heim & Binder, 2012).

As Lund et al. (2011) point out, this social causation pathway is one principle driver behind the negative cycle of unsatisfactory mental health outcomes and social exclusion. The other one, working in the opposite direction, is the social drift pathway. According to this hypothesis, people with mental disorders are "at increased risk of drifting into or remaining in poverty through increased health expenditure, reduced productivity, stigma, and loss of employment" (p. 1502).

Overall, the negative cycle resulting from these two pathways has an utterly detrimental impact on human development. Even though the evidence for this general pattern is quite robust, the precise causal mechanisms vary according to the specific disorder and context and sometimes remain difficult to identify due to the complexity of factors and interactions involved (Lund et al., 2011).



**Figure 1: Negative cycle of social exclusion and mental disorders**



*Source: elaboration by the authors*

## 2.4 The mental health gap

Given the considerable impact of mental disorders on individual and social well-being, the lack of attention to mental health is nothing short of dramatic in most countries. In fact, mental health might be “the most neglected area of health policy and programming” (Yamin and Rosenthal, 2005, p. 296).

In line with the spending gap introduced above, there is a very large treatment gap. However, information on the proportion of people with mental disorders receiving appropriate treatment, which would allow to systematically quantify this gap, is largely unavailable from government sources or scientific literature, especially when it comes to LMICs (Eaton et al., 2011). This fact, in turn, is symptomatic for a larger evidence gap in the field of mental health. One of the few large-scale psychiatric epidemiological studies that included data from LMICs found that in every country studied, at least two-thirds of people with mental disorders had not received any treatment (Thorncroft, 2007). A different study cited by the WHO (2010b) concluded that in LMICs, between 75% and 85% of people with severe mental health conditions do not have access to needed treatment. Even in high-income countries (HICs), where dedicated resources are disproportionately higher, the percentages range from 35% to 50%. In addition to the lack of appropriate services and other structural barriers, perceived need and stigma on the patients' side play major roles in shaping this considerable treatment gap (Andrade et al., 2014).

## 3 HIV/AIDS and social mobilisation

The Acquired Immune Deficiency Syndrome (AIDS) was first recognised as a new disease in 1981 in the United States, when reports of rare opportunistic infections among homosexual men started to increase in New York and California (Sharp & Hahn, 2011). The first cases were reported almost exclusively among homosexual men. Only a few months later, towards the end of 1981, first cases were reported among injecting drug users. An untreated HIV-infection leads to very severe physical and neuropsychiatric symptoms within a few years, making it socially disruptive in many ways. Its first occurrence among already marginalised groups, its unknown etiology as well as its severe symptoms rendered the AIDS epidemic a perfect breeding ground for stigma and discrimination. From initial descriptions of the illness as “gay-

related immunodeficiency” by researchers (Altman, 1982) to its framing as “wrath of god syndrome” by religious communities (Law, King, Zitek, & Hebl, 2007), from the very beginning the HIV-epidemic was as much a social issue as it was a medical one.

### **3.1 The HIV movement**

Since this first outbreak, a powerful advocacy movement quickly gained momentum, first in the United States and, ultimately, on a global level. The HIV movement took different shapes around the world and had to face context-specific challenges in each country. Yet, the basic traits of today's global movement were largely defined by the events in the United States, where it first took off. Thus, for the purpose of analytical parsimony, the present study lays a clear focus on the movement's inception and development in the United States context. Together with HCM Strategists, the non-governmental organisation (NGO) FasterCures (2011) discerns five principle elements that shaped the HIV-movement's effectiveness: attention, knowledge and solutions, community, accountability and leadership.

#### **Attention**

When it comes to raising attention, radical activism joined forces with the inherent urgency of the illness itself. As one of the founders of the NGO ACT UP (AIDS Coalition To Unleash Power), Larry Kramer, puts it: “[w]e were dying, and we looked like we were dying” (FasterCures & HCM Strategists, 2011, p. 10). Thousands of people laid their bodies down on Wall Street, others threw condoms into a Cathedral. This kind of public action, in combination with effective media strategies, raised an unprecedented awareness for the disease.

#### **Knowledge & Solutions**

The messages of the HIV movement did not come from anybody, they came from informed stakeholders and patients themselves. This concept of “expert patients” was a fundamental innovation and has shaped HIV advocacy and its impact on many levels (Cataldo & Kielmann, 2010). By gaining expert knowledge in biomedical, legal and administrative questions, activists started to become substantial contributors in their dialogues with decision-makers - they were part of the discussion. This approach sustainably changed the way affected individuals interact with government agencies, research institutions, corporations and the media.

#### **Community**

During the first years of the epidemic, activists started to gather and to organise, founding ACT UP in 1987. This NGO not only played a central role in channelling advocacy, but also in creating a strong sense of community among the activists. There were numerous committees, workshops and weekly meetings that brought people together and thus catalysed individual motivation and social capital. The resulting collective identity conferred considerable momentum to the movement and helped to sustain it over time. Certainly, the HIV movement did not start from scratch in this regard. There were significant overlaps with the LGBT (Lesbian, Gay, Bisexual, Transgender) community, which already drew on strong social networks and proved to be very open in embracing people with HIV from outside their original circles (FasterCures & HCM Strategists, 2011). ACT UP was a central catalysing agent, but the informal networks throughout society were just as important.

#### **Accountability**

Getting public attention and fostering science and policy literacy among patients and activists were seminal and crucial first steps. Yet, what shaped the success of the HIV movement in the long term was its focus on specific demands and a clear overarching strategy. Even more importantly, this focus was sustained through a vigilant follow-up on the demands that drew on clearly defined benchmarks. Ultimately, this clear definition of success made it possible to hold the central stakeholders accountable. This coherent outside strategy would not have been possible without an effective inside strategy, which brought about

clearly defined roles within the movement. Whether it be big picture strategists or highly specialised scientists, the orchestrated action of a very diverse set of actors was pivotal to the HIV movement's strength.

### **Leadership**

From community organisers to members of congress, the HIV movement hugely benefited from people assuming leadership roles on different levels and in different areas. This is especially relevant as the different elements of the movement require different leadership skills and thus, diversity in leadership. Strong leadership within the HIV movement ultimately translated into strong leadership within government agencies and other stakeholders in the United States.

The intricacy and importance of the relationship between social movements and political leadership becomes very clear in a comparative analysis of South Africa and Brazil carried out by Nunn, Dickman, Natrass, Cornwall and Gruskin (2012). These countries were among the first to be heavily impacted by the HIV epidemic and had similar prevalence rates around 1990. After years of diverging policy responses, Brazil nowadays counts with a prevalence rate of 1%, while it has climbed up to 18% in South Africa. The HIV movement in South Africa was strong and managed to provide access to treatment and prevention to many people through private initiatives and agreements. Nevertheless, the comparison carried out by Nunn et al. indicates that even such a strong movement is ultimately limited in its scope as long as government and civil society exist in isolated spheres. The overall perviousness of a society is crucial to the multi-level and multi-sector diffusion of leadership which, as mentioned above, plays a key role in producing change.

## **3.2 HIV activism and access to treatment**

From the very beginning, access to treatment was a central pillar of the HIV movement. The very first big action carried out by ACT UP on 24<sup>th</sup> March 1987 took place on Wall Street (AVERT, 2014b) and was directly aimed at Burroughs Wellcome, the pharmaceutical company producing the first ever antiretroviral (ARV) Azidothymidine (AZT). Its price of \$10,000 per patient per year was harshly criticised, as it placed the drug beyond the reach of many (Kapstein & Busby, 2013). Besides the price of ARVs, clinical trial design and acceleration of drug approval processes were also a major concern. There were important campaigns against stigma and discrimination, but access to treatment was the spearhead of HIV activism and, as examined further on, still plays a very particular role in today's response.

### **3.2.1 Cultural framing: attacking Big Pharma**

The way an issue is framed sets the arena for a conflict and, as such, might be easily overlooked in retrospective when focusing on the conflict itself. Yet, a compelling frame is an essential element for any social movement to succeed (Kapstein & Busby, 2013). The HIV movement made access to treatment the central issue and attacked the pharmaceutical industry and its patent rights for hindering this access. This strategy allowed to draw on a simple and direct causal line: patents lead to high prices, high prices hinder access, and lack of access to treatment kills people. Citing the work of Keck and Sikkink (1998), Kapstein and Busby (2013) point out that, historically, there seem to be at least two kinds of frames that have proven recurrently successful on a global level. The first are frames relating to legal equality of opportunity. None of the above authors is able to provide a full explanation for this observation, but, as they state, there seems to be a certain expansion of liberal values around the world. For the present study, this kind of frames is not particularly relevant, as the focus of interest lies on outcome equity, which often requires, but significantly exceeds legal equality of opportunity. The second are frames based on "issues involving bodily harm to vulnerable individuals, especially when there is a short and clear causal chain (or story) assigning responsibility" (Keck & Sikkink, 1998 *quoted in* Kapstein & Busby, 2013, p. 61). This kind of framing, quite openly, plays a key role when comparing HIV and mental health advocacy. The universal appeal of these frames, according to the above authors, lies in their ability to "avoid both the indifference resulting from structural relativism and the arrogance of cultural imperialism" (Kapstein and Busby, 2013, p. 61).

The urgency of the then rapidly fatal disease turned the access to treatment quite naturally into an immediate top priority, ahead of long-term challenges like prevention or stigma and discrimination. Nevertheless, even within this exact same priority setting, the issue could have been framed very differently. For example, patents and prices could have been accepted as appropriate, regarding both aspects as part of a system where very high and in many occasions futile investments into drug research are made possible through a patent system that allows to charge high prices once a successful drug has been developed. In this case, it would have been the responsibility of the different governments to provide health financing mechanisms that allow to pay for treatment and infrastructures that allow for its distribution (a framing obviously favoured by pharmaceutical companies). In this case, there still would have been a relatively simple causal chain within the main line of confrontation. Yet, the crucial difference is that instead of a handful of pharmaceutical companies in a highly concentrated market, there would have been a myriad of different actors in each and every country responsible for, as of this framing, “killing people”. Given such a framing, uniting and gaining momentum against a clearly defined opponent would most likely have turned out quite difficult for the HIV movement. Having the pharmaceutical industry as an opponent, on the other hand, proved to be a very valuable asset in this regard. Besides being clearly discernible and easy to circumscribe, the pharmaceutical industry also made itself an easy moral target through several fateful strategic decisions, like suing the government of South Africa in 2001 over the South African Medicines and Medical Devices Regulatory Act (Cooper, Zimmerman, & McGinley, 2001).

### **3.2.2 Windows of opportunity: the pharmaceutical industry in the 1990s**

From the late 1980s through the 1990s, the pharmaceutical industry underwent deep structural changes that made it particularly amenable to transformative action (Kapstein and Busby, 2013). After years of exponential growth in the post-war era, for the first time the pharmaceutical industry was forced to re-evaluate business structures when costs for research and development (R&D) increased and fewer new drugs found their way onto the market. It was an unprecedented phase of mergers and acquisitions (M&A) that spawned a global oligopoly in the pharmaceutical industry. While this high industry concentration conferred certain power to producers, it also allowed to turn around the entire market by turning around just a handful of stakeholders. The M&A activities required shareholder and regulatory approval as well as, quite often, legislative changes and thus offered a point of entry for activist pressures.

### **3.2.3 Tackling treatment costs**

Incessant pressure from activists, NGOs (e.g. the Clinton Foundation) and governments of LMICs, most notably South Africa and Brazil lead to flexibilities and exemptions in international pharmaceutical patents (AVERT, 2014a). Above all, it was the threat and ensuing entry of generics to the market that ultimately achieved the long sought-after major price reductions that would pave the way for scaling-up treatment on a global level. Brazil started the large scale production of generics for highly active antiretroviral therapy (HAART) in private and public facilities in 2000, followed by Indian generics manufacturer Cipla only a few months later. As a consequence, the world price per patient per year fell from over \$10,000 to under \$300 within just one year. Plummeting prices not only made scaling-up affordable, but removed a major rationale for generalised inaction in many countries.

## **3.3 State of the HIV response**

In 2011, the United Nations General Assembly (UNGA) issued the Political Declaration on HIV/AIDS, in which it set ten specific targets to be reached until 2015.

When looking at the latest Joint United Nations Programme on HIV/AIDS (UNAIDS) report from 2013(b), it is possible to discern a pattern regarding the progress on these targets. The greatest progress so far could be achieved on the largely biomedical targets. The coverage with ARV therapy for the prevention of mother-to-child transmission (PMTCT) could be increased from 57% in 2011 to 62% in 2012 and UNAIDS

was optimistic about the proposed 90% reduction of new infections among children between 2009 and 2015. Between 2011 and 2012, the number of people on treatment increased from 8.1 to 9.7 million, which represented 34% of the 28.6 million people eligible according to the new 2013 WHO guidelines<sup>3</sup>. The number of tuberculosis-related deaths among people living with HIV declined by 36% since 2004, putting the goal of a 50% reduction until 2015 in reach. This achievement is closely related to the scale-up of ARV treatment, which substantially reduces the risk of contracting tuberculosis.

The largely biomedical targets are followed by those related to funding, free movement and service integration. Resources dedicated to the HIV response have increased steadily over the last years and reached \$18.9 billion in 2012. The number of countries, territories and areas with HIV-related travel restrictions was reduced from 96 to 43 between 2000 and 2013. Most notably, China repealed its restrictions in 2010. When it comes to the integration of HIV in health systems and broader development efforts, 70% of countries report that they are on track to achieve the national commitments.

Finally, the latest UNAIDS report reveals that the targets related to social and behavioural phenomena are the ones that have recorded the least progress to date. New infections among adults, used by UNAIDS as a proxy for sexual transmission, have decreased from 2.8 million in 2001 to 2.0 million in 2012 in LMICs (29%). The largest part of these reductions took place before 2007, with the numbers completely stagnating between 2007 and 2011. Missing information on infection rates among marginalised groups like sex workers and men who have sex with men continues to be a major problem. According to UNAIDS, the world is not on track of meeting the 2015 target of a 50% reduction. When it comes to people who inject drugs, UNAIDS estimates that there has been little change over the past years. As with other marginalised groups, reliable data is scarce and fragmented. Even in the case of the 51 countries that reported prevalence data for people who inject drugs, estimates were usually derived from local surveys with limited external validity. Similarly, for gender inequality the data situation is utterly problematic and, furthermore, UNAIDS does not seem to have clear benchmarks to measure real live progress. There is an increase in gender-related policies, but low country response rates and, where reported, high rates of gender violence indicate that progress on the ground is lacking far behind. The same is true for the target related to stigma and discrimination, where clear benchmarks are missing and progress, if recorded at all, appears to be frequently limited to high-level policies and legislation. Even on the legislative level, facts are alarming. For example, seven of the ten major recipient countries of the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) and more than 50% of the 88 recipients of the President's Emergency Plan For AIDS Relief (PEPFAR) continue to criminalise same sex relations.

### 3.4 Outlook

The global number of people living with HIV has increased steadily over the last years and reached 35.3 million in 2012. To a large extent, this increase is due to the continuous expansion of life saving ARV treatment, from practically zero in the early 2000s in LMICs, to 9.8 million in 2012. Applying the WHO 2010 guidelines that were in place when the 2011 Political Declaration on HIV/AIDS was passed, this would constitute a coverage of 61%. Yet, as mentioned above, according to the new 2013 guidelines, a coverage of 34% has been reached. Corresponding to this massive increase, the number of AIDS-related deaths has fallen to a record low of 1.6 million in 2012.

Even though the number of new infections also could be reduced in the past years, 2.3 million people newly contracted HIV in 2012. At this point, one of the central issues becomes obvious: even the unprecedented scale-up of the last years does not hold pace with new infections. The 2.3 million new infections in 2012 were met by an additional 1.6 million people on treatment. Furthermore, fewer AIDS-related deaths and an ever increasing number of people living with HIV necessarily will require a corresponding increase in resources for life-long treatment. Even taking the 2010 WHO guidelines to

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<sup>3</sup> Among other aspects, these guidelines recommend an earlier initiation of treatment and thus considerably expand the base of eligible individuals (WHO, 2013).

determine eligibility and assuming a constant annual decrease in new infections of 5%, Over (2011) estimates that the global costs for treatment alone will raise to \$50 billion in 2030 (constant 2009 US\$). The magnitude of this figure becomes clear when looking at the totality of global Official Development Assistance (ODA), which according to the Organisation for Economic Co-operation and Development (OECD) (2014) reached an all-time high at \$134.8 billion in 2013.

Furthermore, a quite straightforward but often omitted fact is that the people officially reported on treatment are not necessarily the same people every year. A systematic review of 32 studies in Sub-Saharan Africa carried out by Rosen, Fox and Gill (2007) found that, on average, ARV treatment programs had a retention rate of 60% after two years. Loss to follow-up was found to be the major cause of attrition, ahead of death. This phenomenon is not only alarming because it indicates inadequate treatment for many people and bears the potential for engendering new drug-resistant strains of HIV, but it also sheds a very critical light on the concept of Treatment as Prevention (TasP). While ARV treatment has been used very successfully for prevention of Mother-to-Child Transmission (PMTCT) for several years, its use for the prevention of sexual transmission gained momentum just recently after a 2011 landmark study found a 96% reduction of HIV infection among serodiscordant<sup>4</sup> heterosexual couples (AVERT, 2014d). These results were celebrated vividly in the international community, especially because they seemed to dissolve the ongoing debate over resource allocation between treatment and prevention. Yet, these results were produced under ideal clinical conditions. A retrospective observational cohort study in China carried out by Jia et al. (2013) found a mere 24% reduction under real life conditions. Even more importantly, in any case it is the effect of a continuous and conscientious treatment regimen that is tested in those studies, not accounting for the above mentioned high rates of loss to follow-up, especially in high-prevalence countries in Sub-Saharan Africa. In addition, these measures are aimed at heterosexual couples reached by advanced treatment programs, assuming low-risk sexual behaviour exclusively within the relationship. These programs not only face substantial limitations in reaching marginalised groups and maintaining an uninterrupted treatment regimen among them, but measures promising prevention independent from behavioural change bear a very high risk of undermining other prevention efforts. Finally, one of the major issues when using treatment as prevention is that a very large proportion of people living with HIV do not know their HIV status. Stigma and discrimination, low perceived risk as well as the lack of adequate infrastructure play a major role in this regard. UNAIDS estimates that globally 48% of people living with HIV know their status (UNAIDS, 2013b). Yet, when looking at the results of in-depth studies for specific regions or countries, this figure is often substantially lower<sup>5</sup>.

HIV treatment scale-up has saved many million lives and has helped to curb one of the biggest public health threats in recent history. Nevertheless, while doing so, the social dimensions of the disease have not received sufficient attention to date. Pulling prevention on the treatment bandwagon through Treatment as Prevention (TasP) is as tempting as it is dangerous. As the previous explanations show, the HIV response will most likely face severe issues of sustainability in the coming years, with treatment costs threatening to not only edge out measures aimed at prevention, social exclusion and behavioural change, but in fact to swallow a significant proportion of overall development resources. There is much to learn from the HIV movement's massive mobilisation, its subsequent institutionalisation and its many successes. Nevertheless, after the initial phase marked by an utter sense of emergency, it seems like the HIV epidemic has now reached a point of a certain "normalisation", at which, through gradual ablation, the social issues at the root of the epidemic gain increasing prominence. When learning from the HIV movement for the field of mental health, it is important to not only learn from its history, but to equally bear in mind the challenges it still is set to face.

## 4 Moving forward on Mental Health

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4 One partner carries the HI virus, the other does not.

5 E.g.: Kenya 16.4% (Cherutich et al., 2012), Southern India 25-30% (Hande, Sambajirao, & Sanjeev, 2014).

## 4.1 Theories of social mobilisation

When drawing lessons from the HIV movement for the field of mental health, it is crucial to adopt a broad analytical perspective in order to capture and adequately analyse the most critical issues involved.

As Goodwin and Jasper (2015) explain, social movements were perceived as profoundly irrational, frightening irregularities within the larger social context until the 1960s by most researchers. As a result of this rather biased view, analyses tended not to go beyond the tactics of leaders to capture the presumably weak-willed masses. Olson (1965) was one of the first to look at social mobilisation from an undaunted angle, exploring the rational processes and interactions behind individual and collective action. *Resource mobilisation theory* takes this *rational-choice approach* one step further to focus on formal organisations, social movement organisations (SMOs), that are regarded to act like businesses that maximise their own utility within a social movement industry (Goodwin & Jasper, 2015). Similarly to the individualistic approaches to stigma conceptualisation introduced above, this kind of rational-choice approaches provides valuable insights into stakeholder behaviour, but fail to account for the structural and cultural aspects involved in sparking and nurturing social mobilisation. Consequently, they mostly come into play regarding questions of costs (4.3.3) and institutionalisation (4.3.6).

A further approach to analysing social mobilisation is *political process theory*, which was first brought forward by Jenkins and Perrow in 1977. Just as resource mobilisation theories attribute social mobilisation to shifts in resource allocations, political process theory explains social upheavals through windows of opportunity created by the state. In both cases, the efforts, characteristics and relationships of activists are relegated to a secondary role. For this reason, political process theory is helpful when analysing favourable conditions and windows of opportunity for social movements to thrive, but not when it comes to developing action-oriented recommendations to foster social change.

The first theoretical approach that significantly contributes to this central purpose of the present study is the one developed by Freeman in 1973. In her analysis of the women's liberation movement, Freeman lays a clear emphasis on the social networks that exist and develop between movement participants (4.3.2). About a decade later, Cohen (1985) was among the first researchers who moved away from rational-choice and strategy analysis to focus on the role of culture. Two of the main issues analysed from this angle are cultural framing (4.3.4) and collective identity (4.3.2). Third, the emotions of protest are a very central element of the HIV movement's success and thereby critical when drawing lessons from its experience. While theories before the 1960s specified emotions very poorly ("the irrational, angry masses"), modern theories emerging thereafter largely neglected this crucial element of protest. This has changed quite recently, with authors like Goodwin, Jasper and Polletta (2000) paying new attention to the emotions involved in social mobilisation (4.3.1, 4.3.2 and 4.3.4).

Overall, the ensuing analysis does take into account early theories of social mobilisation focused on rational choice and the political process, but lays a clear focus on more recent theories of social networks, culture and emotions to engender action-oriented policy recommendations.

## 4.2 Mental Health as a policy issue

Mental health is a highly complex policy issue and it is therefore crucial to examine some of its most important characteristics before embarking on the comparison with the field of HIV. Mackenzie's (2014) work is particularly useful in this regard, as this author is the first to combine an extensive stakeholder survey with a systematic analysis of problem tractability and network effectiveness, both central issues when exploring social mobilisation in the field of mental health.

**Table 1: Characteristics of mental health as a policy issue according to Mackenzie**

Characteristics	Explanation and implications for tractability	Barrier /
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	<b>of mental health as a policy issue</b>		<b>Opportunity</b>
1	Heterogeneity	There is a diverse range of mental health conditions, symptoms, causes and treatments. The conditions affect very different demographics and there are dissenting attitudes regarding diagnosis and treatment. Policies in the field of mental health tend to entail highly cross-sectoral implementation processes. This heterogeneity is an overarching factor that significantly complicates the tractability of mental health as a policy issue.	Barrier
2	Stigma	The pervasiveness of stigma in the field of mental health substantially increases the behavioural change required of policy-makers and the public.	Barrier
3	Agency of the service user	To date, people with mental disorders are only loosely organised and strong service user networks are still scarce. This increases the diversity of the target group's behaviour.	Barrier
4	Lack of data	There is a general lack of evidence (e.g. prevalence, context-specific treatment options, perceptions, need, etc.), which negatively impacts the availability of valid technical theory and technology.	Barrier
5	Under-diagnosis	Mental disorders often go undiagnosed or even unrecognised by the patients themselves. The disorder might not be culturally acknowledged or manifest itself in a way not directly observable from outside. Moreover, there is a continuum between health and illness that further complicates diagnosis. Overall, the under-diagnosis of mental disorders increases the diversity of the target group's behaviour and negatively impacts the availability of evidence.	Barrier
6	Individualised nature of treatment	There is no simple "catch-all" solution for the treatment of mental disorders, which decreases the perceived availability of valid technical theory and technology for policy-makers.	Barrier
7	Low financial investment	Low financial investment is a result of other characteristics, but has its own negative impact on research and advocacy strength.	Barrier
8	Role of the informal sector	Treatment of mental disorders often takes place in the informal sector in low- and middle-income countries. This means that there are significant behaviour changes required by the actors engaged in the current systems.	Barrier
9	International commitments and engagement	Mental health receives increasing attention from the public as well as from international organisations like the WHO, the World Bank and other smaller, but consistent donors. The upcoming years are likely to hold important policy opportunities in the field of mental health.	Opportunity
10	Effectiveness of networks	Even though the variety of networks in the field of mental health is still small, those that exist are very well developed and possess significant internal policy cohesion. Possible explanations provided for this phenomenon are the uniting effect of stigma towards outside actors and the self-selecting process that leads to an increased proportion of strongly intrinsically motivated individuals. There is strong individual leadership in the sector and a substantial amount of professional expertise through the pronounced involvement of technical specialists. A low number of strong networks can be an advantage, as it lends the few existing networks an authoritative voice within their respective national contexts.	Opportunity

*Source: elaboration by the authors based on Mackenzie (2014)*

As *Table 1* illustrates, Mackenzie finds most characteristics of mental health as a policy issue to create significant tractability barriers. All factors combined lead to a situation where evidence is scarce, prevalence and need underestimated and available solutions blurred. The target group behaviour is highly diverse and a substantial behavioural change would be required by stakeholders and the public to better address mental health issues on a policy level. Nevertheless, Mackenzie also finds two of the characteristics to create important opportunities. The international political environment is currently changing and mental health is starting to receive increasing attention from several key stakeholders. This means that the upcoming years are very likely to offer new windows of opportunity and entry points for social mobilisation. In order to take advantage of these opportunities, the strength and expertise of the few existing networks is a powerful asset to be expanded upon. Besides these two characteristics identified by



Mackenzie as sources of opportunity, there is also significant potential awaiting behind some of the barriers created by other characteristics. These barriers, opportunities and hidden potentials will be discussed in detail in the following section, drawing on the HIV movement's experience to find a path ahead.

### 4.3 Learning from the HIV movement

Focusing on market transformations, Kapstein and Busby (2013) identify four major factors that have contributed to the HIV movement's success: the addressing of costs, effective cultural framing, the creation of effective institutions and, as they call it, a coherent “ask”. The following sections pick these four factors up while significantly expanding upon them in line with the experiences of the HIV movement explored in *Chapter 3* as well as the broad analytical perspective laid out in *Section 4.1*.

#### 4.3.1 Mental health, HIV and stigma

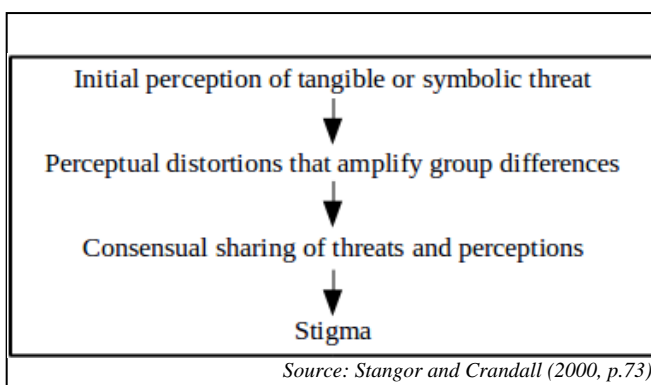
A large proportion of severe and prominent illnesses in history was associated with some kind of stigma, especially when the etiology was unclear and/or overlapped with certain group characteristics or cultural beliefs. Whether it be leprosy in medieval Europe, the 1892 outbreak of typhus fever in New York blamed on Jewish immigrants (Gorman, 2012), or the dramatic marginalisation of people with disabilities in modern day India (World Bank, 2007), stigma and health have been connected throughout human history.

Mental health, in this regard, has always played a conspicuous role, with beliefs about demonic possession or similar cultural constructs present all over the world. Similarly, AIDS has been associated with heavy stigma, discrimination and all kinds of superstitions since it was first observed in the early 1980s. In fact, the pervasiveness of stigma and discrimination in these two fields is salient to a degree that “[i]t is difficult to pick up a consensus report on mental illness or HIV/AIDS without finding numerous references to the ways the stigmatisation of these health conditions undercuts prevention and treatment efforts” (Stuber, Meyer, & Link, 2008, p. 351). Stigma is the strongest link between both fields and, as such, needs to be explored in detail before moving on to further conclusions.

##### The social psychology of stigma

Even though there is an abundant literature on the nature and consequences of stigma, analyses of the mechanisms of initial formation are very scarce not only regarding health, but in overall stigma theory. Stangor and Crandall (2000) draw on the more extensive literature on prejudice and discrimination to conceptualise stigma origination and consolidation. While, according to these authors, perceptual theories are very useful at explaining how an initial stigma is accentuated through cognitive bias, consensual theories help to understand how a majority of members in a society come to judge the same dimensions as meaningful and thus consolidate the stigma in question. Yet, as they find, it is functional theories that provide the most significant insight into the initial formation of stigma. Most notably, Stangor and Crandall (2000) focus on threat as one of the most important drivers behind stigma formation. From this point of view, stigma is regarded as a reaction of self-protection in the face of tangible (e.g. status, wealth, health, etc.) or symbolic (e.g. values, beliefs, ideology, understanding of the world) threats.

**Figure 2: Stigma formation and consolidation**



This conceptualisation seems particularly useful when applied to health issues, where stigma can be understood as a coping and protection strategy. First, by creating a simple causal explanation, the illness is taken out of the threatening realm of the unknown. By making sense of it, the individual regains a certain type of control and thus, feeling of security. Second, by excluding and stigmatising a determined group, the individual creates a distance between themselves and the threatening phenomenon.

The degree of stigma is heavily dependent on the perceived severity or disruptiveness of an illness and on the perceived personal responsibility that is attributed to it (Stangor & Crandall, 2000; Pescosolido, Martin, Lang, & Olafsdottir, 2008). Furthermore, perceived individual responsibility might be considerably amplified as a reaction to a symbolic threat to belief systems. There is ample evidence that people have a strong motivation to believe in a just world (Stangor & Crandall, 2000). When this belief is challenged by the factual world, people create stigma in order to resolve the cognitive dissonance. For example, blaming poor people for being poor discards any structural inequities and thus restores mental ease in the stigmatising individual. In the case of HIV and mental health, a threat to personal beliefs about a just world might increase perceived individual responsibility, which, in turn, has the potential to increase the severity of stigma that originated as a reaction to other factors.

Tangible threats play a certain role when it comes to mental health. As Davey (2013) points out, people with mental disorders are often perceived as dangerous and unpredictable. The media with its proclivity for dramatic and violent stories certainly has a considerable impact in this regard (Pescosolido et al., 2008). More importantly, though, there is a very disruptive and exceptionally opaque symbolic threat emanating from mental disorders. People identify with their minds to such a degree that a dysfunction of it swiftly leads to questions about the nature and meaning of their very existence. "Losing one's mind", in this sense, embodies an ultimate loss of control. Labelling people with mental disorders as substantively "different", i.e. drawing a clear line between "us" and "them", partly restores a sense of security. Furthermore, as mentioned above, the etiology of mental disorders involves a complex combination of biological, psychological and social factors that is still to be fully understood. Even though effective treatments have been developed for many disorders, the exact mechanisms of effect are often unclear. In the case of antipsychotics, for example, there are still a lot of questions about how and why there is such a considerable heterogeneity of response (Case et al., 2011). This opaqueness further accentuates the perceived threat associated with mental health conditions. Quite evidently, mental health is a term that encompasses many different disorders, each of which entails different context-specific consequences for social interactions and stigma. Nevertheless, the present study focuses on a general notion of stigma regarding mental disorders for two reasons. First, despite the differences, there is also a strong nonspecific label effect regarding mental disorders (Corrigan, 2004). Second, and most importantly, the present study is interested in social mobilisation in the field of mental health. With a focus on collective action, common stigma and group identity are far more decisive than variations in the stigmatisation of different diagnostic groups.

When it comes to HIV, there is a straightforward perceived tangible threat of infection, which is often significantly heightened through incorrect beliefs about modes of transmission. Yet, the HIV-epidemic also has such profound metaphysical and sociocultural implications that it has previously been described as an "epidemic of signification" (Treichler, 1987). AIDS was first observed in the early 1980s among homosexual men and was even referred to as "gay cancer" by some in the first years after its discovery (AVERT, 2014c). Since then, the history of HIV has been strongly entangled with questions about sexuality, gender, race, socioeconomic inequalities and many other fundamental societal issues.

### **Stigma and power**

A very crucial aspect of stigma that has not received due attention in many analyses is power (Stuber et al., 2008). As Link and Phelan (2001) put it,

[w]hen people think of mental illness, obesity, deafness, and having one leg instead of two, there is a tendency to focus on the attributes associated with these conditions rather than on power differences between people who have them and people who do not. (p. 375)

Yet, stigmatisation does require power to be realised and works as a key mechanism in reproducing inequalities. In both fields, HIV and mental health, disparities in social, political and economic power play a critical role in establishing stigmatising beliefs. As Parker and Aggleton (2003) note, a narrow focus on individualistic conceptualisations of stigma so far has led to a neglect of this kind of structural dimensions and thereby hindered the development of effective responses in the field of HIV. Rather than focusing on the conditions that produce exclusion, according to these authors, research has strongly focused on the beliefs and attitudes of those who stigmatise. Though the previously introduced framework for stigma etiology of Stangor and Crandall has strong roots in social psychology, it is very compatible with a structural analysis. Both approaches explain two different parts of the same story. Questioning or deviating from an existing social order inherently entails symbolic and tangible threats to dominant actors. The next two steps in Stangor and Crandall's framework, perceptual distortion and consensual sharing, are equally dependent on existing power relations and concentration, as dominant actors possess more social and material resources to influence cultural framing and public perceptions. While the present study does not deny the importance of individualistic approaches in understanding stigma, it does recognise their inadequacy for informing effective intervention strategies by themselves. The ensuing comparison between HIV and mental health is aimed at producing action-oriented recommendations and thus, necessarily, adopts a strong focus on the structural aspects associated with stigma and, in a broader sense, social mobilisation.

As previously described, people with mental disorders are a vulnerable group by themselves and share important overlaps with other recognised vulnerable groups. The same is true for HIV, where most at risk populations include injecting drug users, sex workers and their clients, men who have sex with men, and prisoners (UNAIDS, 2008). HIV and mental health are both fields that, like few others, exemplify the social dimension of health. In both cases, an effective response needs to reach far beyond the medical realm and address the very basic ways society deals with social exclusion. HIV advocacy has come a long way since the early 1980s and it seems there are many lessons to be learned from the successes and shortcomings of this exceptional movement for the field of mental health, which is in dire need of social change.

#### **4.3.2 Social networks and group identity**

As in other fields, mental health stigma can manifest itself in the form of public stigma, self-stigma and label avoidance (Corrigan and Wassel, 2008).

**Public stigma** refers to attitudes that the public holds towards people with mental disorders and is usually contested through protest, education or contact. Corrigan and Wassel point to evidence that protest, while potentially very effective in inducing immediate behavioural change, is not always conducive to transforming the underlying stigmatising attitudes. Similarly, the rather small effects on attitudes yielded by measures focused on education are usually not maintained over time. Contact, on the other hand, presents the strongest evidence base for substantially and sustainably influencing public stigma.

**Self-stigma** refers to people with certain marks internalising the associated stereotypes. Corrigan and Wassel describe the "loss of self-esteem and self-efficacy caused by self-stigma (...) as the anchor of one end of a continuum, with personal empowerment anchoring on the other end" (p. 46). Self-stigma can be tackled through cognitive-behavioural therapies that reduce irrational self-statements and harmful attitudes. More importantly, though, group identification is the strongest factor in fostering this kind of empowerment.

**Label avoidance** refers to people who have not been diagnosed with a mental disorder avoiding the corresponding health services so as not to be marked with the label. Though more research on label avoidance is needed, it is to a large extent a consequence of public and self-stigma and thus might be reduced alongside these phenomena.

Corrigan and Wassel's findings show that people coming out and coming together empirically tends to be the most effective way to tackle self-stigma. Furthermore, as public stigma is most effectively reduced

through contact, the proactive behaviour of affected individuals resulting from reduced self-stigma has equally substantial ramifications. Stigma and discrimination have been addressed relatively effectively by the initial HIV movement in the United States, but continues to be one of the largest barriers in the global response, especially in LMICs.

Social networks and group identity have been absolutely pivotal to the HIV movement's strength throughout its history and provide some very valuable insights into this discrepancy. The epidemic first spread among men who have sex with men and, briefly thereafter, among injecting drug users. This means that there was a pronounced spatial concentration of affected people, mostly in a few urban centres in the coastal regions of the United States. There was also a significant social concentration, with many preexisting ties among those who contracted the virus. The LGBT movement was already well organised and, as previously described, proved to be very open in taking in people living with HIV from other backgrounds.

This is not the case for mental health. Even when people are aware of their disorder, which is not always the case, they often assume that they are alone with their condition. Moreover, even if both is given, geographic dispersion and stigma seriously hinder the establishment of social ties.

Yet, as Freeman (1973) points out, this kind of microstructural preconditions are absolutely vital for movement emergence. In her analysis of the women's liberation movement, she deduces three propositions from the gathered data and comparisons with other movements.

First, the author concludes that “[t]he need for a preexisting communications network or infrastructure within the social base of a movement is a primary prerequisite for “spontaneous” activity. Masses alone don't form movements, however discontented they may be (...)” (p. 794). One might add that repression itself does not automatically entail discontent. People are not necessarily aware of an injustice while submerged in the cultural systems that inform them. Communications networks thus might not only serve as a catalyst for already existing discontent, but considerably contribute to creating this discontent in the first place by making people aware of structural injustices. As such networks are scarce in the case of mental health, a much higher organising activity is required as compared to the field of HIV. Furthermore, this effort must deal with the diverse set of mental disorders and their complex symptoms, which tend to render social interaction more complex.

Second, Freeman proposes that these communications networks need to be co-optable, i.e. “be composed of like-minded people whose background, experiences, or location in the social structure make them receptive to the ideas of the specific movement” (p. 794). This proposition, though very useful, is too narrowly formulated for the present study. While the reception of ideas is a critical issue, one might argue that it depends as much on the ideas themselves, how they are framed and how they are communicated (see 4.3.4.) as on the characteristics of the recipients. In fact, the experience of the HIV movement shows that while, especially in the beginning, a general like-mindedness of many participants can certainly be a significant advantage, the movement also drew a lot of its strength from its increasing diversity that emerged after the first few years. A common cause and a common fate were strong catalysts for the creation of a new group identity that was highly inclusive of a very wide array of educational, political, ethnic and social backgrounds. In the case of mental health, this initial advantage of a relatively like-minded group of people is not given. Thus, social mobilisation in this field needs to compensate for the lack of pre-existing co-optability, increasing the receptiveness towards new ideas by adopting highly diversified communication strategies in order to reach the equally diverse set of potential participants. Once mobilisation has gained momentum, the diversity of backgrounds might, just as in the case of HIV, turn out to be a valuable asset.

Third, Freeman proposes that, given a co-optable network, a precipitant is required. This might be either a crisis that galvanises the network into action or the activity of individuals who specifically attempt to construct a movement. As so often, both factors overlap in reality. Yet, when comparing HIV and mental health, clear tendencies can be observed. While HIV emerged and spread suddenly, leading to the death of many people within a short period of time and within already established social circles, mental disorders

have existed throughout human history and are spread throughout society. Instead of a sudden crisis, there is lingering ailment. As a direct consequence, social mobilisation in the field of mental health will need to rely much more on the organising efforts of single actors to achieve the same level of mobilisation that was sparked quite naturally amidst the emergency of the HIV epidemic.

While social networks are closely linked to common identities, the formation of a strong group identity goes beyond social ties and has played its own very decisive role in the HIV movement's history. The associations formed by the HIV movement were much more than interest groups, they were ends in themselves<sup>6</sup>. Similarly, meetings were much more than a market place for interests, but public spaces that helped forge strong solidarities and a common identity among the participants. In this context, emotions have played a key role from the very beginning. While emotions commonly referred to as “negative” like fear and anger have fuelled radical political action, “positive” emotions have played a very crucial role in strengthening the social ties that formed the basis for this action. As previously described, ACT UP meetings regularly involved group activities and social events, which offered a lot of joy and excitement to participants and fostered the creation of a group identity based on affective ties.

The level of group identity that emerged among HIV activists is not likely to develop on the same aggregated level in the case of mental health due to the demographic, geographic, social and medical diversity and dispersion in the field. Yet, group identity on a micro-level could be just as effective in the context of a decentralised mental health response. Community based approaches like those discussed in the following section have the potential to tap into various existing identities and expand on them in an inclusive manner, just as the HIV movement did in regard to the LGBT community.

Among all the points of comparison, social networks and group identity might be the ones where both fields differ the most. Though the backlog regarding these two aspects is considerable in the field of mental health, so are the strengths of the already existing networks (see 4.2). Furthermore, mental disorders are highly prevalent among the general population and thus the amount of potential participants is substantial<sup>7</sup>. Hence, behind these barriers, there is significant potential awaiting.

Social networks and group identity were the fuel that powered HIV activism, without which any strategy would have lacked momentum. The HIV movement has shown that affected individuals themselves have the utmost potential to bring about change. Thus, advocates in the field of mental health should focus on people who are stigmatised first and on those who stigmatise second, conferring foremost priority to organising and connecting affected individuals. Education is a very attractive strategy, especially because it is easy to export. Nevertheless, it can only be complementary to measures aimed at transforming the power relationships that underlie stigmatisation. In this context, communications systems based on simple mobile technology can play a decisive and revolutionary role in overcoming geographic and social dispersion. This kind of systems has been pioneered very recently in different areas of public health (e.g. Holeman, 2014), including for the monitoring of mental disorders (Matheson, 2014). Yet, the use of these technologies to foster the creation of social networks and mobilisation among people affected by mental disorders in low-income settings remains an area for future research and development.

### **4.3.3 Addressing costs, expanding treatment**

A key to the HIV movement's success was that it addressed the costs of its demands and worked to bring about a favourable cost-benefit analysis for the different stakeholders. As Kapstein and Busby (2013) find, this was not only a crucial element of the HIV movement's achievements, but a factor that should be addressed by any social movement to further its cause.

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<sup>6</sup> Compare with Cohen's (1985) criticism of resource mobilization theory.

<sup>7</sup> Based on data from the WHO's World Mental Health Survey Initiative, Kessler et al. (2007) estimate the lifetime prevalence of mental disorders in 17 countries in Africa, Asia, the Americas, Europe, and the Middle East. The results range from 12% in Nigeria to 47.4% in the United States, with an inter-quartile range of 18.1-36.1%. Even though this kind of figures can only provide a rough estimate, the prevalence of mental disorders is substantial by any measure.

In the case of HIV, treatment in the narrow sense is exclusively biomedical. Yet, as previously described, treatment adherence and thus its effectiveness strongly depend on social and psychological factors. In the case of mental disorders, biomedical treatment is only one potential part of a comprehensive, effective intervention. Thus, not only treatment adherence, but treatment effectiveness from the very start depends on how well it takes into account the complex social setting each individual is embedded in, including issues of stigma. On the one hand, this fact renders the situation far more complex than in the case of HIV, where ARVs are offered as the clear-cut (and only) treatment solution. On the other hand, it also opens up significant opportunities. While the progress regarding pharmacological approaches to the treatment of mental disorders has significantly slowed down in recent years, there have been considerable advances when it comes to psychosocial approaches. First, this means that many basic effective medications like antidepressants or antipsychotics are already available in cheap generic form. Second, while biomedical treatment without psychosocial support tends to be of limited effectiveness, cost-effective psychosocial approaches by themselves can produce substantial improvements in the quality of life of affected individuals (Lund et al., 2011; Chatterjee et al., 2009).

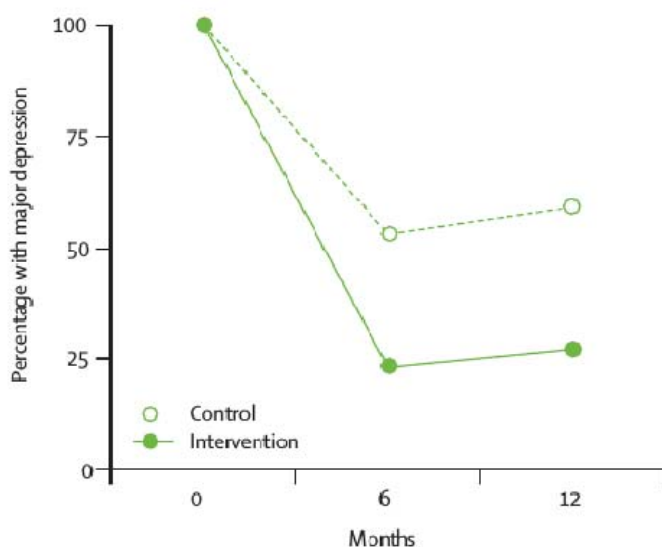
One example for a very promising psychosocial approach in LMICs is the *BasicNeeds Mental Health and Development* model, which was launched in 2000 and has since received increasing attention in the international development community. This approach does not treat people with mental disorders individually, but aims at restoring an integration between them and their communities (BasicNeeds, 2015a). Affected individuals are enabled to assume an active role within society, regaining social capital and influence. In Nepal, a case study of the BasicNeeds model carried out by Raja et al. (2012) showed considerable results only eight months after program initiation. Of those who did not engage in any income-generating activity at program start, 15% started earning an income. Of those who did not participate in any productive work (e.g. household) before, 46% began such work. Nevertheless, the authors also found that self-advocacy was still very poorly developed due to geographic dispersion and the reluctance of pre-existing advocacy groups to take in people with mental disorders (compare 4.3.2). In rural Kenya, Lund et al. (2013) evaluated the effects of participating in the BasicNeeds program on the outcomes of a cohort of people living with severe mental disorders in circumstances of poverty. Their results show substantial and statistically significant improvements in all health, social and economic variables after two years.

Another equally promising example are interventions based on the training of lay people. There are many instances of highly successful approaches that tap into community resources and synergies with other health services to treat major depression in low-income countries. The Thinking Healthy Program, for one, provides female community health workers in rural Pakistan with a two-day training in basic cognitive behavioural therapy, which these integrate in their routine visits with pregnant women and new mothers (Rosenberg, 2014). When assessing the impact of this intervention, Rahman, Malik, Sikander, Roberts and Creed (2008) found drastically reduced rates of major depression in the treatment group as compared to the control group<sup>8</sup>.

### **Figure 3: Impact of the Thinking Healthy program in Pakistan**

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<sup>8</sup> The control group also registered a substantial decline, which is not to be mistaken for a non-intervention scenario. As the authors state, visits by community health workers were absolutely consistent and thoroughly monitored for the study, which is usually not the case in the studied area. The regular visits by health workers by themselves are very likely to have an independent positive effect.



	Intervention	Control	ICC	Adjusted odds ratio (95% CI)*	p value
6 months	57/418 (23%)	211/400 (53%)	0.047	0.22 (0.14-0.36)	<0.0001
12 months	111/412 (27%)	226/386 (59%)	0.037	0.23 (0.15-0.36)	<0.0001

Source: Rahman et al. (2008), p. 905

Besides this training of community agents, there are also programs that very successfully rely on peers as therapists (Rosenberg, 2014). In Pakistan and India, the Thinking Healthy programs are shifting to such an approach, in which mental health professionals recruit and train women with similar backgrounds as those they will be treating. As Vikram Patel from the London School of Hygiene and Tropical Medicine puts it: “This is a human resource widely available in every population” (Rosenberg, 2014).

In both fields, HIV and mental health, the response faces the treatment of chronic conditions that depends on a stable, consistent infrastructure. The experience with HIV has shown that, once gathered the low-hanging fruits, expanding treatment to the most marginalised groups and maintaining a consistent regimen among them through conventional structures can quite quickly turn into a Sisyphean task. Just as in the case of HIV, the field of mental health struggles with issues of treatment seeking and treatment adherence. Besides public stigma, self-stigma and label avoidance, the trust and confidence in available treatments for mental disorders and in the delivering institutions plays a key role in this regard. The scope of this factor and its implications for public health became very evident during the 2014 outbreak of Ebola in Western Africa. The response has been substantially hindered by rumors of national governments, international donors or international organisations like the Red Cross experimenting on people, stealing their body parts or practicing euthanasia in the treatment camps (Jerving, 2014; Whitfield, 2014). Community and peer-based approaches that not only include medical, but also social and economic interventions have a very high potential to overcome this kind of trust issues. Furthermore, instead of confronting the informal sector through formalised structures, informal networks can be used as an asset and be tapped into by this kind of approaches, reducing the behavioural change required by incumbent actors.

Hence, cost-effective and scalable treatments for mental disorders are available. Focusing on simple, community-based approaches is not only cost-effective and sustainable, but it allows to account for specific cultural contexts and tap into the rich social resources of local communities. Standardised education programs, sometimes based on fixed western cultural preconceptions, have not had the desired effect so far when it comes to HIV prevention. This should be a lesson for the field of mental health in order to find more promising solutions, especially taking into account that, as mentioned above, not only prevention and treatment adherence, but treatment itself depends on interventions being sensitive to the social environment. In many cases, the mere acknowledgement of and attention to a disorder by trained lay people can substantially improve people's lives, turning the negative cycle of mental health and poverty into a positive one of increased well-being and societal participation.

In the case of HIV, one big technological breakthrough, ARV therapy, has been exported and expanded throughout the world. For mental health, an utterly heterogeneous issue, this is not an option. Even if there were such catch-all solutions for mental disorders, prevention as well as treatment seeking, adherence and expansion to marginalised groups would most likely face the same issues as the HIV response. The experience with HIV shows that when target groups are marginalised by society, the demand side of treatment is a critical bottleneck that has to be addressed before supply side oriented treatment expansion can have any significant effect. This is even more relevant in the field of mental health, where compliance not merely consists in the regular intake of medications, but in an active participation and engagement of affected individuals.

HIV and mental health are both fields where treatment of the respective health conditions has the potential to reduce the stigmatisation associated with them (Corrigan, 2004; Castro & Farmer, 2005). From a psychosocial perspective, effective treatment reduces the perceived threat associated with an illness or disorder as well as the perceived “otherness” of affected individuals. Yet, stigma reduction through treatment places the responsibility on the stigmatised individual, not on the public (Corrigan, 2004). Consisting in a unilateral decision to stigmatise less on behalf of those who stigmatise, the direct process through which treatment reduces stigma does not tackle the underlying structural inequalities. In an indirect way, though, treatment can play an important role in reducing stigma in the field of mental health. By mitigating the socially and cognitively disabling effects of mental disorders, treatment has the potential to foster personal empowerment and group formation and thus contribute to a sustainable shift in power relations. It is important to keep this distinction in mind when developing stigma reduction strategies. Though treatment can play a very substantial supportive role in the field of mental health, maybe even more so than in the case of HIV, it cannot be the essence of a sustainable stigma reduction strategy. The experience and current state of the HIV response shows that making people less different by itself does not solve the basic societal issue of socially excluding those who are.

Measures focused on community integration might not cure or perfectly mitigate some of the neuropsychiatric symptoms, but they have the highest potential to improve health in a comprehensive sense for the largest proportion of people with mental disorders, including those most marginalised by society. The WHO defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (WHO, 1946). When looking at this definition, it becomes clear that simply exporting the Western model of psychiatric care might neither be the best nor the most cost-effective solution for LMICs. In this context, it is also crucial to beware of incentive structures and retribution systems currently in place in many HICs that favor cost intensive interventions. While for the HIV movement addressing costs meant attacking the pharmaceutical companies behind the only treatment solution, in the field of mental health, addressing costs might very well consist in resisting the temptation to export Western models of psychiatric care in favor of flexible, socially oriented approaches.

#### **4.3.4 Cultural framing: a rights-based approach**

Unlike few others, the HIV movement has exemplified the importance and power of effective cultural framing. Activism in the field of mental health can learn from this experience and, instead of tackling issues as and where they are, actively engage in defining a powerful frame within which to have the discussion. In the case of HIV, using “death” as one of the strongest and most universal foundations for such framing has proven to be very effective in gaining support and resources for the expansion of treatment. Yet, the effectiveness of this quite specific frame is to a large extent limited to the issue around which it has been evoked, the reduction of the costs at which pharmaceuticals sell ARVs. It is important to bear in mind that many issues in the field of HIV, like prevention, stigma and social exclusion, largely fall outside this traditional frame around treatment access and, as ARV prices have been dramatically reduced, increasingly surface as major challenges ahead.

The WHO (2010b) estimates that 844,000 people die by suicide every year and, as previously described, mental disorders can have a severe and often fatal impact on physical health. Though it might be tempting



to base framing in the field of mental health on this kind of fatal consequences, it is not likely to be nearly as effective as in the case of HIV. First, while the connection between HIV and death is clear-cut and immediate, in the case of mental health there is a multitude of factors involved and there are complex and long causal pathways for each disorder. Besides the difficulty of quantifying and effectively communicating the effects of mental disorders on physical health, suicide is associated with its very own stigma and tends to be covered up and underreported across most countries. Second, a frame exclusively focused on saving lives is very likely to run into the same issues as in the case of HIV when dealing with social exclusion and the transformation of underlying power structures. Third, the effectiveness of the framing brought forward by the HIV movement roots in connecting the most relevant actors that can bring about change to the axiological basis of the argument through a strong and uninterrupted causal chain (“pharmaceutical companies kill people”). In the case of mental health, emphasising the deadly consequences of disorders might evoke a diffuse feeling among the public that something has to be done. Yet, given the complexity and heterogeneity in the field, it is not very likely to lead to any coherent ask (see 4.3.5) towards specific actors.

Instead, it seems like for the field of mental health, focusing on the Human Right to Health might render the most transformative and sustainable impact. Such an approach becomes increasingly crucial in the face of what London (2008) describes as the growing global phenomenon of regarding “health policy decisions as service delivery issues, requiring technical inputs to reach the best “evidence-based” decisions” (p. 71), rather than acknowledging health as a right. As he puts it, “[s]uch reframing of health away from its nature as a socio-economic right strips health policy-making of its inherent elements of power and the contestation that goes with the recognition of power” (p. 71).

The Right to Health finds early mention in the 1946 WHO Constitution (WHO, 1946) and the 1948 United Nations Universal Declaration of Human Rights (UNGA, 1948), with only the former providing a concrete definition of health and, therein, explicitly including mental health. The 1966 International Covenant on Economic, Social and Cultural Rights (ICESR) (UNGA, 1966) reaffirms “the right of everyone to the enjoyment of the highest attainable standard of physical and mental health”. Even though the Covenant already includes vague indications as of the steps necessary to realise this right, the stipulations still stay on a rather abstract level. It is not until the General Comment by the UN Committee on Economic, Social and Cultural Rights in 2000 that the Right to Health recognised in the Covenant is put into concrete terms (WHO & Office of the United Nations High Commissioner for Human Rights [OHCHR], 2007).

The General Comment already goes beyond the boundaries of health care and acknowledges the central role of the social determinants of health. This tendency is taken a step further in the 2007 Convention on the Rights of Persons with Disabilities (CRPD) (UNGA, 2007), which, for the first time, specifically addresses the intersection of social exclusion and health from a human rights perspective and puts structural inequities at center stage. The question of when a mental disorder does and does not constitute a disability is a highly subjective matter and depends as much on the environment as on the individual condition itself<sup>9</sup>. As defined in the Convention, “[p]ersons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (Article 1). In the context of such an inclusive definition, any mental disorder might be considered a disability if sufficiently persistent and disruptive<sup>10</sup>. Hence, the CRPD, together with previous treaties and agreements in international human rights law, constitutes an important basis for constructing a human rights framework for action in the field of mental health.

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9 Note that even the term “mental disorder”, favoured throughout the present study for its largely technical connotation, is not devoid of interpretative margin and axiological implications. One might argue that precisely this technical-medical connotation over-individualises mental health and thus neglects the social discretion in segregating “healthy/normal” from “ill”.

10 Disability can only be assessed case by case and the criteria depend on the specific context. In the United Kingdom, for example, a mental disorder is considered a disability if it has substantial adverse effects on the ability of a person to carry out normal day-to-day activities and has lasted or is likely to last one year or more (Government of the United Kingdom, 2015).

Yet, as Burns (2009) finds, the introduction of equality legislation and even the equal access to health services by themselves not only are likely to be of limited effectiveness, but have the potential to even create reactionary effects by drawing attention away from unchanged or increasing substantive inequality. As the author puts it, a human rights approach to mental health, especially as articulated in the CRPD, “requires a paradigm shift (...) away from a public health approach in its conventional sense” (p. 21). The paternalism of such a public health approach in its conventional sense is still palpable in the 2000 General Comment introduced above, where all elements of the Right to Health are depicted as something that the duty bearer (the State) is required to offer to the rights holder (individual), without truly addressing the underlying power structures that determine the realisation of these rights.

The transformation of these power structures is at the core of an effective human rights framework and, ultimately, of the present comparison of HIV and mental health. In this context, it is not only important that health be acknowledged as a human right, but how exactly it is conceptualised as such. As London (2008) finds after reviewing evidence from South and Southern Africa regarding HIV activism, whatever the modality of operationalising human rights - holding government accountable, pro-actively developing policies and programs or securing redress for those whose rights have been violated -, it can only be effective if sustained by strong social mobilisation. As long as the Right to Health is conceptualised merely as some standard for state conduct, it fails to fulfill its inherent purpose of social change. Besides this active agency of the user, London also points out that an effective health rights strategy needs to involve health professionals and move from individualised claims against providers to claims against health systems. Failing to prioritise such mutual sharing of objectives, according to London, risks to set up a “fruitless antagonism between the aggrieved rights holder and the disempowered duty bearer without recognizing the structural constraints imposed by a health system poorly geared to respond to a human rights demand” (p. 72-73).

Framing mental health as a human right and conceptualising this right in terms of active agency and shared objectives adds depth to all the preceding points discussed so far in this chapter.

First, a human rights perspective strengthens the case for a teleological approach to stigma. As Thornicroft and Kassam (2008) explain, research on stigma and mental health, in general...

...has focused on hypothetical rather than real situations (Sayce, 2000), shorn of emotions and feelings (Crocker et al., 1998; Fiske, 1998), divorced from context (Corrigan et al., 2004a), indirectly rather than directly experienced (Repper and Perkins, 2003), and without clear implications for how to intervene to reduce social rejection (Corrigan, 2004). In short, most work on stigma has been beside the point. (p. 191)

From a human rights perspective, on the other hand, any discussion of stigma should be measured by the practical implications it engenders for transforming power structures and by how well it takes into account the emotions and subjective perceptions of the different stakeholders. In this context, Thornicroft and Kassam (2008) as well as Burns (2009) call for a shift of focus from stigma to discrimination, as this would allow to place people with mental disorders in parity with respect to anti-discrimination legislation and the human rights agenda (Burns, 2009). Yet, even though an increased focus on discrimination is crucial, it seems like such a simple “shift” would not be expedient for an effective human rights framework. From all the previous considerations regarding the HIV movement and the field of mental health, it seems like both attitudes (stigma) and actual behavior (discrimination) play a key role in overcoming existing barriers. Thus, a human rights based approach not only requires to pay increased attention to the inherently practical issue of discrimination, but to equally engage in strengthening an action-oriented discussion of stigma.

Second, a human rights perspective adds an important dimension to approaches focused on community integration, which have been introduced previously in terms of cost-effectiveness, cultural adaptability and scalability (see 4.3.3). As Yamin and Rosenthal (2005) put it,

[f]rom a human rights perspective, people are entitled to live in and receive care in the community not because it is more efficient, but because all human beings develop their identities within social contexts, and have rights to work and study, as well as be with family and friends. (p. 297)

Furthermore, a human rights perspective not only adds depth to the previously introduced utilitarian reasoning for community based approaches, but, through active user agency, also delivers a powerful mechanism for effective implementation.

Third, a human rights perspective entails crucial implications regarding social networks and group identity. In a human rights framework that focuses on its inherent nature as a mechanism for the transformation of power structures, social networks and group identity become the foundation on which such framework catalyses action and social change. As Chopra and Ford (2005) note, the current development paradigm often favors blueprint approaches, which tend to reinterpret development issues “into ‘engineering’ problems amenable to modern management techniques” (p. 385). In such a context, “community engagement” or “participation” is often limited to community organisations delivering or implementing preconceived messages or programs. This kind of community engagement is substantively different from the *active agency* introduced above, which entails a transformation of power structures and active participation in the agenda setting process. An approach that focuses on this kind of active agency has been denominated as “biological” by Taylor (Taylor, 2001 *in* Chopra and Ford, 2005). Rather than on the content of a specific program, such an approach shifts the emphasis to the characteristics of a community's organisations and institutions. Consequently, external actors assume a facilitating role, supporting communities in defining their own identities, goals and means. In this context, social change is catalysed “by “creating spaces and channels for people to discuss amongst themselves – and by connecting community groups that do not usually communicate” (p. 386). This, of course, not only applies to the communication between specific groups within a local community, but to communication channels between all kinds of stakeholders, including government agencies, NGOs or international organisations and donors. Without such multi-level and multi-sector communication, the creation of shared objectives is very unlikely to thrive.

As becomes clear from these observations, some of the favorable factors that emerged naturally during the initial HIV movement in the United States might be fostered today in the field of mental health by using an accordingly conceptualised human rights approach as a framework for action. The HIV movement pioneered active agency of affected people, most famously through the “expert patient”. This active agency rested on powerful social networks which, in turn, were fortified by a strong group identity. The HIV movement has shown that, once empowered, affected people can be their best and most innovative advocates. Channeling the efforts of these advocates, in turn, requires the formulation of a coherent ask.

#### **4.3.5 Coherent ask**

One of the central elements of the HIV movement's success was that it provided a coherent ask behind which activists could coalesce (Kapstein & Busby, 2013). ARV treatment arose organically from this grass-roots movement as the most effective and urgent intervention at the time. At the same time, a narrow focus on this intervention rather than on the process of social mobilisation that led to prioritise it has nowadays led the HIV movement to a dangerous impasse in many LMICs, where grass-roots re-prioritisation is urgently needed. Hence both, the HIV movement's successes as well as its shortcomings, provide a valuable lesson for the field of mental health in this regard. Any approach focusing on specific interventions would probably very quickly get lost in the medical, social and cultural complexities and heterogeneities of global mental health. It would most likely not even get close to such an impasse on a very high response level as occurs in the field of HIV, which due to its medical characteristics is much more amenable to the above mentioned blueprint approaches. Instead, it seems like focusing on the process of social mobilisation itself might be the most promising path to advance mental health on the international development agenda. It is not necessary for all actors in the field of mental health to pursue the same set of priorities as long as they can agree on one coherent, common ask that lends strength to all their diverse

aspirations. Drawing on all the previous explorations, it seems like a basic, but strong coherent ask in the field of mental health might be most successful if it focuses on the following two elements:

1. A human rights based approach conceptualised in terms of active agency and shared objectives.
2. Connecting users and improving multi-level and multi-sector communication channels.

In such a context, rather than pushing for concrete demands and interventions, external actors like NGOs, international development agencies or multilateral organisations first and foremost should focus on providing the channels and connecting the different actors in order to create momentum. Besides this crucial facilitating role, external actors have an important part to play in providing technical support to governmental actors and providers, including measures aimed at the dismal situation regarding evidence and data.

It is crucial to note that the heuristic openness of such an ask does not and should not implicate axiological relativism. To the contrary, focusing collective demands on the basis of social mobilisation requires absolutely clear definitions and conceptualisations, even more so than in the case of targeting a specific intervention, where the inherent simplicity of the demand limits the risks of dispersion.

On the one hand, it is absolutely crucial for a coherent ask to be open to different cultural contexts, because “[b]oundaries between health and disease, and between mind and body, are drawn in different ways in different cultural traditions” (Fernando, 2014, p. 30). Most LMICs have a gruesome history of colonialism, during which indigenous systems for mental health were systematically suppressed while the systems of psychiatric treatment introduced by the colonial powers were rarely taken up and, in any case, consisted of oppressive asylums in the European style (Fernando, 2014). Hence, a coherent ask in the field of mental health not only faces the challenge of reviving and reintegrating local approaches to mental health in LMICs, but, just as in HICs, to phase out the 19<sup>th</sup>/20<sup>th</sup> century Euro-American approach to mental health focused on detention and medicalisation.

On the other hand, simply strengthening participation and communities in a presumably impartial way also implies a significant risk of reinforcing pre-existing power asymmetries. As Cromwell explains:

With their emphasis on consensus, the institutions created as part of participatory development initiatives – whether committees, user groups, community action planning groups and so on – can exacerbate existing forms of exclusion, silencing dissidence and masking dissent. (Cromwell, 2003 *quoted in* Chopra & Ford, 2005, p. 388)

This means that the process of strengthening communities and home-grown interventions needs to be selective and targeted to a certain extent. For example, gender-based discrimination has been and continues to be one of the major barriers to an effective HIV response. In the field of mental health, this matter is even more complex, as gender issues have a very strong and intricate influence on the development and manifestation of mental disorders (Rosenfield & Mouzon, 2013). Furthermore, just as in the case of HIV, gender-based discrimination is likely to be an important obstacle to mental health advocacy. Evidence in this area is still scarce and a lot more research is needed. In any case, the provision of channels and the strengthening of user networks and communities needs to be based on a thorough gender analysis and specifically tackle the related issues. The same is true for discrimination based on ethnicity, sexual orientation, religion, age, class or any other form of social exclusion that might exist in a given community.

Hence, a coherent ask in the field of mental health has to find and constantly re-evaluate a balance between being culturally open and sensitive while at the same time remaining assertive in the defense of the human rights of all individuals. A basic, but consistent and generally accepted international legal framework can provide important guidelines in this regard and thus, should be part of a coherent ask in the field of mental health.

Another issue that needs to be accounted for is the fact that stigma and other social phenomena vary significantly among disorders and specific contexts (Thornicroft & Kassam, 2008). This means that, while fostering the creation of networks and group identity, it is absolutely vital to address the need for a coherent group behaviour while at the same time avoiding to conflate and neglect the differences between disorders. In a wider sense, this also applies to other sources of heterogeneity. The HIV movement very effectively tackled this issue by internalising many key debates, thus being able to act coherently towards outside actors while at the same time attending to its internal diversity.

Furthermore, when fostering community integration, it is vital to beware of confounding integration with assimilation. Just like making people less different through treatment (compare 4.3.3), trying to force people with mental disorders into the pre-existing structures within a given community does not solve the basic issue of social exclusion. Instead, it is important to conceptualise community integration as a process of rapprochement and increased communication and understanding among all its members. Finally, when pushing for active agency of users and strengthening communities, there is a very pivotal distinction to be made “between community agency reinforcing rights mechanisms and the unsavory practice of substituting government obligations with NGO or community action” (London, 2008, p. 68). If this important conceptual distinction is omitted, the government might very well be absolved from some of its responsibilities instead of being held accountable for them, which is a key element of an effective human rights approach.

In conclusion, the complicated task ahead of formulating a coherent ask in the field of mental health might be most successful when focusing on the foundations of social mobilisation within an effective human rights framework centred around active agency and shared objectives. This heuristic openness needs to be steered through very clear and specific conceptualisations of all the major issues involved in order to avoid the manifold pitfalls such an approach entails.

#### **4.3.6 Institutions**

Besides the addressing of costs, effective cultural framing and a coherent ask, the creation of effective institutions is the fourth major factor identified by Kapstein and Busby (2013) as playing a key role in the HIV movement's success. According to these authors, a revolution took place in the field of HIV at the beginning of the 2000s, with major shifts of resources and organisation building. As they stipulate, it was mostly the creation of The Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) in 2002 and the President's Emergency Plan For AIDS Relief (PEPFAR) in 2004 that allowed to tackle the “demand side failure” (p. 170) in expanding global HIV treatment. Again, Kapstein and Busby focus on market transformations and thus analyse institutions in terms of their function to stabilise markets. Yet, beyond these stabilising functions, there is certainly a wide array of organisations that have significantly influenced and brought forward the HIV response, whether it be UNAIDS, the WHO, large private foundations like the Bill and Melinda Gates Foundation or the myriad of highly important small NGOs around the globe. Both from resource mobilisation and political process perspectives (see 4.1), the predominance of the GFATM and PEPFAR as massive international funding mechanisms reflects, to a certain degree, the leading role of large-scale, blueprint treatment expansion in the international HIV response. The current international institutional setup in the field of HIV has been a crucial factor in reinforcing and solidifying the impact of the HIV movement. Yet, the impasse reached by the current HIV response (see 3.3 and 3.4) calls for a transformation of this setup in the upcoming years in order to meet the challenges ahead.

In the field of mental health, the institutional setup is currently in a state of intense development. The WHO has assumed a central role, most notably through the Mental Health Action Plan 2013-2020, the “first ever real political commitment to mental health by the 194 Member States of WHO” (Mackenzie, 2014, p. 18). This action plan includes important provisions to strengthen the international and national legal and policy frameworks for a rights-based approach in the field of mental health. By and large, a certain leadership of such large international organisations has the potential to make significant contributions and catalyse change. Yet, as discussed previously, there is no substitute for strong social mobilisation that

tackles underlying power structures. Furthermore, the pronounced heterogeneity in the field of mental health calls for a more diverse institutional setup.

In this regard, networks like the Movement for Global Mental Health (MGMH) have the potential to play an important role in the upcoming years. This particular network started in 2007 with a Call for Action published in the first Lancet series on global mental health and has now “grown to a membership of around 200 institutions and 10,000 individuals, many of who are actively involved” (Movement for Global Mental Health, 2015). Also the Mental Health Innovation Network (MHIN) and NGOs such as BasicNeeds with its empowerment approach show that diversity and flexibility are compatible with coherent and coordinated action.

Overall, developing an institutional setup in the field of mental health that combines leadership and concerted action with a decentralised, context-specific and culturally sensitive approach to mental health is one of the major challenges ahead in the quest for promoting mental health and well-being worldwide. In this context, it is absolutely vital to always be aware that simply scaling-up and exporting certain interventions, like in the case of HIV, might be utterly counter-productive in the field of mental health.

## 5 Conclusion, policy recommendations and model for action

The HIV movement has revolutionised health advocacy and drawn significant attention through its radical and innovative strategies. Yet, simply recommending these strategies to advocates in the field of mental health would not be expedient in any way. The HIV movement has shown that, once social mobilisation has gained momentum, advocates have the utmost potential to pick up and develop the instruments that best suit their specific causes and contexts. Hence, the present study has focused on the roots of social mobilisation and how the momentum and the experiences of the HIV movement can provide lessons to foster this mobilisation in the field of mental health. The factors explored as significantly contributing to the HIV movement's success are:

**Figure 4: Key factors in the HIV movement's success**

• Stigma and power	• Accountability
• Social networks and group identity	• The addressing of costs
• Emotions and culture	• Effective cultural framing
• The expert patient, active agency and the diffusion of leadership	• A coherent ask
• Multi-level and multi-sector communication channels	• Institutions
	• Windows of opportunity

*Source: elaboration by the authors*

Just as its successes, the HIV movement's shortcomings provide an equally valuable insight. The fact that the strong focus on ARV treatment has led the HIV movement to a dangerous impasse in many LMICs reinforces the importance of the social processes that informed its successes in the first place. In this sense, the present recommendations for the field of mental health might also turn out quite useful in reinvigorating social mobilisation in the field of HIV, especially in high-prevalence contexts in Sub-Saharan Africa.

Overall, based on the entire preceding analysis, the following **policy recommendations** can be presented for moving forward on mental health:

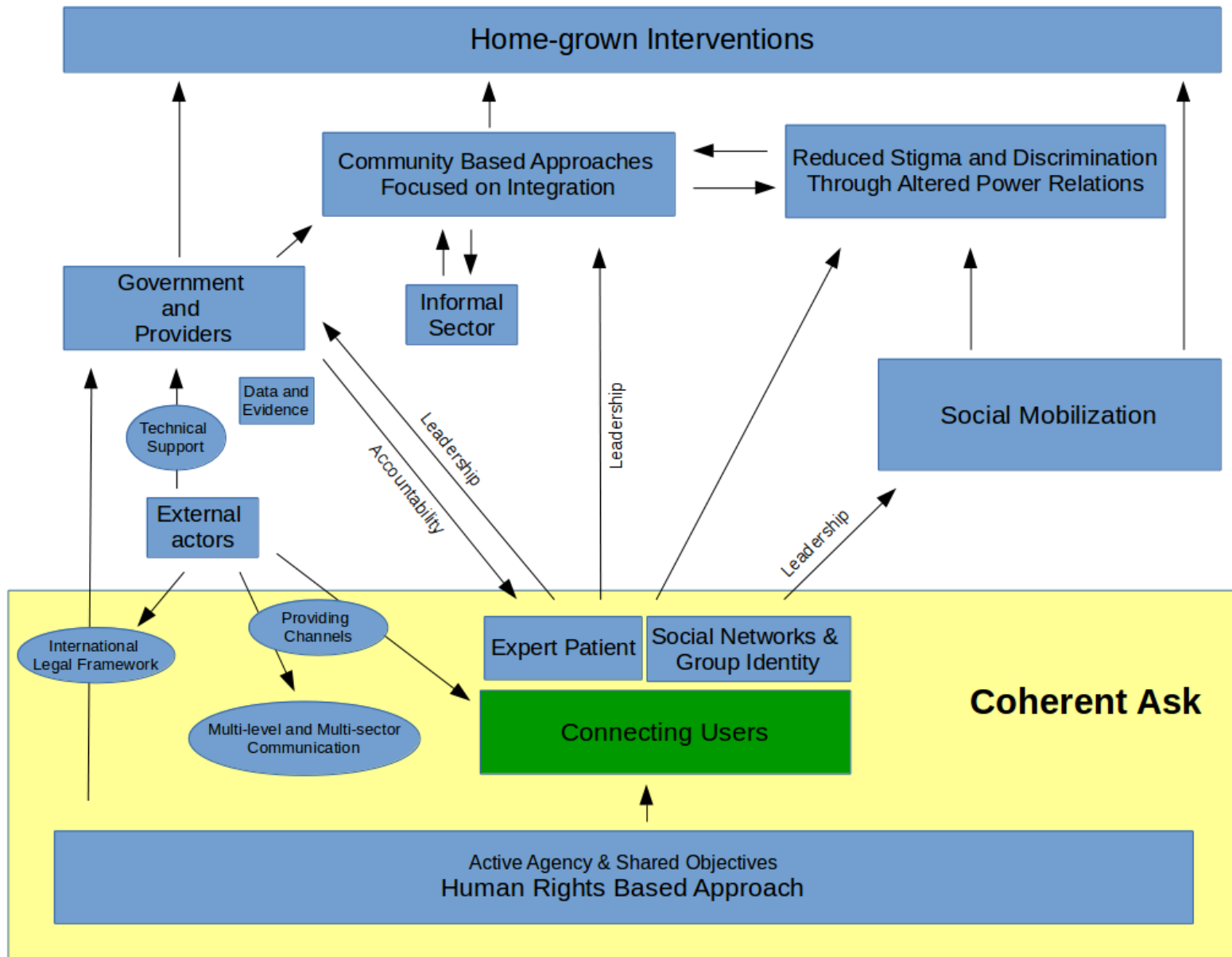
1. Promote the development of social networks and group identity among people with mental disorders as well as multi-level and multi-sector communication channels in order to foster social mobilisation.
2. Adopt a human-rights based approach to mental health specifically conceptualised in terms of active agency and shared objectives.
3. Promote community based approaches focused on community integration, paying very close attention to pre-existing forms of social exclusion.
4. Include and actively engage the informal sector instead of working against it.

In this context, the **role of external actors** (NGOs, international organisations, development agencies, etc.) is threefold:

1. Foster and provide the channels to connect users, strengthen social mobilisation and nurture the multi-level diffusion of patient leadership.
2. Provide technical support to governments and providers, especially targeting the evidence gap in the field of mental health.
3. Engage in the establishment of an effective and clearly defined international human rights framework, including both legal provisions and the transformation of power structures to enable the effective realisation of rights.

The **model for action** in the field of mental health resulting from these recommendations as well as all the previously discussed issues is illustrated in *Figure 5*.

Figure 5: Moving forward on mental health – a model for action



Source: elaboration by the authors



This model for action accounts for all the characteristics of mental health as a policy issue identified by Mackenzie (2014):

**Heterogeneity:** By focusing the coherent ask on the basis of social mobilisation and a consistent human rights framework, the model allows for a diversity of home-grown, context-specific interventions to branch out.

**Stigma.** The model calls for a consistently action-oriented approach to stigma which lays a clear emphasis on transforming power relations by connecting users.

**Agency of the service user.** By insisting on a human rights framework that is specifically conceptualised in terms of contesting existing power structures, the presented model puts the agency of the service user at centre stage.

**Lack of data.** This is where external actors play a crucial role through technical cooperation.

**Under-diagnosis.** Community based approaches focused on community integration as well as the connection and empowerment of users provide an important opportunity to increase mental health literacy and a more open discussion of issues related to mental health. Such an environment, in turn, significantly increases the opportunities of appropriately diagnosing mental disorders within the specific social and cultural contexts.

**Individualised nature of treatment.** By involving the informal sector and fostering culturally sensitive, home-grown interventions, local (e.g. religious) approaches can be combined with other medical and non-medical interventions in order to account for the individual and social dimensions of mental health. Furthermore, active user agency is a powerful tool to adjust interventions to the actual needs of affected individuals.

**Low financial investment.** Increasing the resources dedicated to mental health is a long-term issue that needs to be sustainably tackled by increasing social mobilisation in the respective countries. Directly providing financial resources from outside does not seem like a promising measure in face of the necessity to build up sustainable, locally owned structures. In the short term, the focus on very simple, cost-effective approaches based on community integration can be used to significantly increase the impact of scarce resources. As the integration of individuals affected by mental disorders progresses, economic payoffs for communities might increase incentives to further invest in interventions.

**Role of the informal sector.** Involving the informal sector plays an important role in the suggested community based approaches.

**International commitments and engagements & effectiveness of networks.** Even though the number of networks is scarce, the existing ones are strong and coherent. The coherent ask suggested in this model is utterly suited for this situation, as it calls for targeting specific leverage points instead of pursuing large scale programs. Such a targeted approach will also be crucial to take advantage of the expected windows of opportunity in the upcoming years.

Nevertheless, the previous explorations also have revealed a number of pitfalls in relation to this model for action that call for a diligent conceptualisation of the issues involved. The most important conceptual differentiations identified are:

**Table 2: Key concepts and pitfalls**

Concept	As required by the model for action	Pitfall
Active agency	Active participation in the agenda setting process	Substitute government obligations with NGO or community action

Human rights	Transformation of power structures	Standard for state conduct
Role of duty bearers and rights holders	Shared objectives: involve health professionals, formulate claims against health systems	Fruitless antagonism between the aggrieved rights holder and the disempowered duty bearer
Movement coherence	Internalise the key debates in order to be able to act coherently toward outside actors while at the same time attending to internal diversity	Conflate and neglect the differences between disorders or other sources of heterogeneity for the sake of unity
Integration	Process of rapprochement and increased communication and understanding among all community members	Integration as assimilation: force people with mental disorders into pre-existing structures
Heuristic openness	Focus interventions on the basis of social mobilisation and community integration in order to achieve an at-scale response consisting of many different home-grown, culturally sensitive interventions, taking into account pre-existing forms of social exclusion and the rights of all individuals	Mistake heuristic openness for axiological relativism and reinforce pre-existing forms of social exclusion through diffuse community strengthening interventions
Treatment	Treatment as empowerment	Treatment to make people “less different”

*Source: elaboration by the authors*

This study has targeted the roots of social mobilisation and, in doing so, probably raised as many questions as it has answered. The concrete operationalisation of such a global model for action requires a significant amount of additional research on the different factors involved, especially within the specific regional, national and local contexts. For example, three salient issues for such further research are:

1. The role of gender in mental health advocacy in LMICs.
2. The use of new technologies to foster networked advocacy in the field of mental health, especially in low-income settings.
3. The ways in which the experiences of LMICs with new community-based approaches can inspire the mental health response in HICs.

Overall, the upcoming years constitute a decisive phase in global mental health that is very likely to bring about important policy opportunities. In this context, further developing a flexible, decentralised and responsive international institutional setup that allows to take advantage of these windows of opportunity is one of the major challenges ahead. In any case, the one lesson from the HIV movement that should always be borne in mind is that no institutional setup, no guidelines and no plan for action can truly succeed if not inspired by the sustainable transformation of power structures through the social mobilisation and active implication of affected individuals.

## 6 References

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