Agenda item 1.4

UNAIDS/PCB (41)/17.18

# REPORT BY THE NGO REPRESENTATIVE



12-14 December 2017 | Geneva, Switzerland UNAIDS Programme Coordinating Board Issue date: 23 November 2017 Additional documents for this item: none

Action required at this meeting - the Programme Coordinating Board is invited to:

See decisions in paragraphs below:

- 67. Recalling decisions from previous Programme Committee Board meetings<sup>1</sup> and welcoming the upcoming discussion at the 42<sup>nd</sup> PCB meeting on ways to monitor the achievement of the financial-related targets of the 2016 Political Declaration on Ending AIDS, including that the proportion of services delivered through community channels should rise to 30% by 2030, and investment in social enablers—including advocacy, political mobilization, law and reform, human rights, public communication and stigma reduction—should account for 6% of global AIDS investments.
- 68. Take note of the report.
- 69. *Request* UNAIDS to support Member States, in collaboration with community based organizations and civil society, to monitor and report on progress made on Fast Track targets disaggregated<sup>2</sup> by key population age and gender, including through the Global AIDS Monitoring.
- 70. *Request* UNAIDS and Member States in partnership with civil society organizations to develop and implement country-level, community-participatory evidence gathering methodologies to identify barriers and measure the levels and quality of access to services for the "left behind populations" who may or may not be sub-sets of the traditional key populations<sup>3</sup> such as, but not limited to, indigenous communities, people living with HIV, migrants, both regular and irregular, and other mobile populations.
- 71. *Request* UNAIDS to produce an update on the 2014 *Gap report* addressing the needs and priorities of populations identified to be left behind in the current response and report back to the 43<sup>rd</sup> PCB.
- 72. *Request* the Joint Programme to facilitate partnerships between Member States and community-based organizations to help ensure effective action to meet both HIV prevention and treatment needs of communities, in particular for "left behind populations".
- 73. *Request* the Joint Programme to develop, implement and monitor, in partnership with communities, a standardized community engagement strategy with indicators aligned with the UBRAF and disaggregated data<sup>4</sup> to help ensure effective action to meet their HIV prevention and treatment needs.

### TABLE OF CONTENTS

I.	INTRODUCTION: PURPOSE AND CONTEXT	4
М	ETHODOLOGY	5
	Limitations of the report	
	Other limitations	5
R	THE FAST-TRACK LANDSCAPE: REPORTED PROGRESS AND THE EALITY FOR KEY POPULATIONS AND OTHER POPULATIONS FACING	
V	ULNERABLE SITUATIONS	
	Case study 1. Gay and other men who have sex with men in Mexico: Targeted approact to increase HIV testing and linkage to care	9
	Missing and left behind: People who are excessively vulnerable The 10–10–10: Who are those left behind?	
	Case study 2: Lesbian, gay, bisexual and transgender persons in Namibia—Reaching people outside the main cities and town	
	. WE KNOW WHY EXTREME AND DISPROPORTIONATE VULNERABILITY XISTS—YET IT CONTINUES TO OCCUR	
	Case study 3. Key populations in India—Strengthening community voices and increasi visibility	ng
	. TURNING THE TIDE: WHAT UNAIDS CAN DO—SUGGESTED ROLES AN	
R	ESPONSIBILITIES	
	Challenges for the UN	
	Call for expanded understanding of vulnerability Inclusion and intersectionality: The way towards ending the AIDS epidemic	
	Renewed attention to previous decision points	
V	RECOMMENDATIONS	22
Α	NNEX 1: WHO IS DISPROPORTIONATELY VULNERABLE: DIVERSITY	
A	CROSS REGIONS AND GROUPS	23
A	NNEX 2: ACKNOWLEDGEMENTS AND PARTICIPANTS	.28
A	NNEX 3: ABBREVIATIONS	30

### I. INTRODUCTION: PURPOSE AND CONTEXT

- The NGO Delegation brings unique, first-hand experiences and perspectives of people living with HIV, key populations and vulnerable communities to the Joint United Nations Programme on HIV/AIDS (UNAIDS) Programme Coordinating Board (PCB). Each year, it develops and presents a report that focuses on one or more issues determined to be of particular interest or urgency for affected communities, non-governmental organizations (NGOs) and other civil society groups that work among, for and with the Delegation.
- 2. The 2017 NGO Report, *The UNAIDS we need must leave no one behind: Getting to zero includes all of us (the 10–10–10)*, seeks to highlight the inequity and neglect faced by individuals and communities that are disproportionately affected by HIV and have long been neglected and in some cases not even recognized in HIV responses at various levels (local, national, regional or global). The reasons for the neglect include a lack of data and other information; social, cultural, economic, legal and political barriers; and stigma and discrimination.
- 3. The characteristics of these individuals and communities differ by context, but in many places they cover distinct populations, sub-populations and communities, such as indigenous peoples, transgender women, and migrant gay and other men who have sex with men. The experiences of and the realities faced by individuals of these and similar groups in vulnerable conditions raise the prospect that they will continue to be ignored in the responses to HIV and that the current 90–90–90 treatment targets and the Fast-Track strategy may never reach them and address their evolving needs. They are being left behind not by chance but by design.
- 4. Some populations, sub-populations and communities face extreme neglect and vulnerable conditions due to stigma, discriminatory legislation, and socioeconomic disparities. This leaves them disproportionately represented among the "10–10–10". They include socially excluded irregular migrants, people in poverty, the elderly, street and other vulnerable children, people in prisons and other forms of incarceration, ethnic members of key populations and indigenous peoples who use drugs. This report aims to highlight their existence and experiences, stressing the urgency to end their isolation and exclusion from HIV responses and, more broadly, from society.
- 5. Not responding to the needs of those in most critical vulnerable conditions would represent a continued failure from the perspectives of equity, human rights and public health, and in terms of responding to the epidemic. This report urges improved and harmonised approaches for continued support for the participation of civil society organizations and communities in HIV responses, as well as for identifying and reaching and including those who have been left behind with concerted efforts tailor made to the different contexts. The Delegation also believes that an improved and sustained impact requires acknowledging the interlinked nature of these different vulnerabilities. That understanding needs to inform HIV responses and improved engagement with communities and individuals in these marginalized populations and subpopulations within them.

### METHODOLOGY

- 6. The 2017 NGO report to the PCB highlights the inequality and neglect experienced by individuals and communities that are disproportionately affected by HIV, yet have been neglected or ignored in different levels of HIV responses for reasons including lack of data about them, social, cultural, economic, legal and political barriers as well as stigma and discrimination. Similar to previous NGO Delegation reports, the current report was informed by interviews, focus group discussions and responses to online surveys which members of the NGO Delegation conducted in July–August 2017 (Annex 1). In addition, a review of relevant literature was conducted, including research papers, reports and other resources from a range of organisations and sectors, including UN agencies. A standardized questionnaire was prepared in English and was translated into Spanish and Russian.
- 7. Almost 300 individuals participated in the consultations. The vast majority of individuals who were interviewed or who participated in focus group discussion were from communities and key populations left behind. Some were from other sectors, however, including a handful from multilateral entities (such as UNAIDS and WHO). Most of the community respondents were from small, local community-based organizations (CBOs), while others were from larger global, regional, or national networks and organizations.
- 8. The report is not intended as a comprehensive review. However, it seeks to shed light on the realities of communities left behind, as well as to contribute to debates and strategies by presenting various viewpoints and experiences, needs and demands of key affected communities and populations that are currently left behind.

### Limitations of the report

- 9. Several limitations should be noted with regards to the three online surveys:
  - Online versions were made available in English and Spanish, and interview questions were translated into Russian only. This may have dissuaded participation by individuals with no or limited facility in either language or may have prompted only basic, brief replies due to language barriers.
  - Several original survey responses (almost one fifth of the total) were incomplete. They were deemed invalid and were not included in any subsequent review. Compared with interviews, online surveys often offer less detailed and sometimes unclear information due to a lack of time for follow-up and clarification.

### **Other limitations**

- 10. Some countries and regions were over-represented in the responses. For example, there were four focus group discussions conducted in India, covering more than 20 people overall, and 16 individual interviews with respondents from the Philippines.
- 11. Multiple respondents from a single organization or network also participated occasionally, either via interviews or online surveys. This yielded several duplicating responses, which may have skewed some of the information.
- 12. Many responses were self-reported and none were validated. None of the information obtained this way could be independently verified.

13. Due to the limitations, the report does not represent the viewpoints of the entirety of civil society and key population networks. It does not and cannot mention or consider all individuals and communities who are disproportionately vulnerable or left behind in HIV responses. Nevertheless, the inputs and summary do provide an important snapshot of the issues, ideas and concerns of individuals and organizations that are doing direct, critical work in community-led advocacy, service provision and support.

#### II. THE FAST-TRACK LANDSCAPE: REPORTED PROGRESS AND THE REALITY FOR KEY POPULATIONS AND OTHER POPULATIONS FACING VULNERABLE SITUATIONS

- 14. There has been growing momentum in the past several years in confronting the global AIDS epidemic. Some of the more recent successes have been driven by the UNAIDS Fast-Track agenda to end AIDS, which emphasizes, among other things, the 90–90–90 targets for 2020:
  - 90% of people (children, adolescents and adults) living with HIV know their HIV status;
  - 90% of people who know their HIV-positive status are accessing treatment; and
  - 90% of people on treatment have suppressed viral loads.
- 15. Highlights were noted in UNAIDS' 2017 Ending AIDS: Progress towards the 90-90-90 targets report in mid-2017: "The data show that substantial progress has been made towards the 90–90–90 targets. More than two thirds of all people living with HIV globally knew their HIV status in 2016. Among those who knew their HIV status, 77% [57– >89%] were accessing antiretroviral therapy, and 82% [60– >89%] of people on treatment had suppressed viral loads. Amid this progress, a major milestone was reached in 2016: for the first time, more than half of all people living with HIV (53% [39–65%]) were accessing antiretroviral therapy."<sup>5</sup>
- 16. The Ending AIDS: Progress towards the 90–90–90 targets report also noted that that seven countries had already achieved the third "90" target regarding viral suppression, with 11 others were "near this threshold".<sup>6</sup> Most of those 18 countries have relatively low HIV burdens. However, two of them—Botswana and Swaziland—have long had among the world's highest burdens of HIV.<sup>7</sup> Findings from an ongoing set of in-depth population HIV impact assessment (PHIA) surveys in sub-Saharan Africa are equally optimistic, with researchers stating in September 2017 that four more countries—Lesotho, Malawi, Zambia and Zimbabwe—were "on track to achieve epidemic control by 2020, through reaching the 90–90–90 targets and expanding HIV prevention."<sup>8</sup>
- 17. Heartening as they are, such results do not tell the entire story, however. Another study of progress toward 90–90–90 targets has urged caution in interpreting results. It notes that although several countries have achieved the targets and others are on the verge of doing so, "in many countries a significant proportion of people living with HIV still remain undiagnosed and therefore unable to benefit from HIV therapy." The authors particularly call for "more efforts to reach these undiagnosed individuals."<sup>9</sup>
- 18. Remarks of this sort underscore the fact that, although the 90–90–90 targets may be valuable advocacy and programmatic goalposts, achieving them should not be construed as solving or controlling HIV. The rest of the road to truly curbing AIDS—and reaching the millions of people who do not have access to treatment or prevention services or support—will be very difficult. That is because many of the major gaps will continue to exist among key and other populations in highly vulnerable conditions who have always been most severely affected by HIV, yet tend to be ignored in HIV responses.

### Box 1. Observation: factors behind limited services for key populations

"Broader economic conditions are behind the fact that public health services including HIV services, are disappearing [...] In the central and southeast European region, services for key populations were built up on Global Fund money, which has left the region, and services mostly collapsed and disappeared."

- Interviewee from a global NGO resource platform

"If we don't disaggregate key populations by age, the adolescent and young members will always be left behind, as they are not able to access services due to cultural, legal and socioeconomic barriers like age of consent or recognition. For example, adolescent sex workers and young girls at institutions of higher learning who are always targets for rich sugar daddies (cross-generational sex), yet these adolescent girls and young women are not recognized as mainstream sex workers." — Youth focus group discussant, Uganda

- 19. UNAIDS defines key populations as: "people who are at heightened risk of contracting HIV due to a mix of epidemiological, economic, legal, cultural and political reasons. In most contexts, key populations include sex workers, people who inject drugs, transgender people, prisoners and gay men and other men who have sex with men. Members of those populations and their sexual partners accounted for 45% of all new HIV infections worldwide in 2015."<sup>10</sup>
- 20. Although this definition highlights key populations' vulnerability, it goes on to add that key populations are *"distinct from vulnerable populations, which are subject to societal pressures or social circumstances that may make them more vulnerable to exposure to infections, including HIV."* The concept is further elaborated in the UNAIDS Terminology Guidelines from 2015:

"Vulnerability refers to unequal opportunities, social exclusion, unemployment or precarious employment (and other social, cultural, political, legal and economic factors) that make a person more susceptible to HIV infection and developing AIDS. The factors underlying vulnerability may reduce the ability of individuals and communities to avoid HIV risk, and they may be outside of their control. These factors may include: lack of the knowledge and skills required to protect oneself and others; limited accessibility, quality and coverage of services; and restrictive societal factors, such as human rights violations, punitive laws or harmful social and cultural norms (including practices, beliefs and laws that stigmatize and disempower certain populations). These factors, alone or in combination, may create or exacerbate individual and collective vulnerability to HIV."

21. In many contexts, women and girls as well as sub-populations among them are highly vulnerable. So, too, is a wide range of other groups and communities that are not specifically described as key populations. (Section 3 of this paper discusses them in greater detail.)

22. The urgency to reach key and vulnerable populations more effectively is evident in the 2017 *Ending AIDS: Progress towards the 90-90-90 targets* report:<sup>11</sup>

"Outside of sub-Saharan Africa, key populations and their sexual partners accounted for 80% of new HIV infections in 2015 [...] Even in sub-Saharan Africa, key populations and their sexual partners are an important part of the HIV epidemic: in 2015, 25% of new infections occurred among this group, underlining the importance of reaching them with services. Globally, gay men and other men who have sex with men accounted for 12% of new infections in 2015, while sex workers and people who inject drugs accounted for 5% and 8% of new infections, respectively. Furthermore, data reported by countries across the world show that HIV prevalence among key populations often is substantially higher than it is among the general population."

- 23. Vulnerable populations continue to face challenges across the HIV treatment and prevention spectrum, including with regards to HIV case identification (e.g. testing); awareness and education; linkage to and retention in care; and legal, social, political and economic barriers. Many of these populations are routinely stigmatized and discriminated against in health-care settings, and they face additional barriers because they are criminalized. Their rights are frequently violated, and their health and social needs go unmet.
- 24. These challenges are reflected in longstanding data and observations showing that, compared with the general population, members of key and vulnerable populations are far more likely to be living with or affected by HIV. They are also more likely to receive inadequate or poor-quality HIV and other health support and services. Exclusion and isolation can be even more extreme among some sub-populations of key populations. These groups are highly context-specific, and include, for example, young men below the age of 18 who have sex with other men and women who inject drugs.
- 25. The following examples illustrate the disproportionate vulnerability and impact such groups and communities experience in different contexts:
  - In a study among 500 people who inject drugs in Bangkok, Thailand, 25% reported that they avoided health services because they were afraid of compulsory treatment. Uptake of HIV services for all survey participants was low.<sup>12</sup>
  - Data submitted as part of Kenya's 2017 HIV/TB funding request to the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund) showed elevated HIV prevalence among key populations: an estimated 29% among sex workers, 18% among gay and other men who have sex with men and 18% among people who inject drugs, while the national HIV prevalence was estimated at 5.6%.<sup>13</sup>
  - Globally, HIV incidence is 10 times higher among female sex workers than in the wider female population.<sup>14</sup>
- 26. The upshot is clear: as countries scale up their HIV programmes to reach the Fast-Track targets, they are unlikely to achieve strong, sustainable results unless they recognize and address the barriers and challenges faced by individuals and populations that are being left behind. They have to respond in ways that improve these individuals' and communities' access to all rights-based HIV prevention, treatment and care. This will require an HIV response that is interlinked with other sectors.

### Box 2. Example of impact: failure of HIV responses to reach all in need

"Many countries including my own Kenya, won't reach those 90–90–90 treatment targets without addressing the issue of HIV drug resistance especially among people in the countryside whose services aren't like ours in the cities where there are centres of excellence. The poverty and long distances travelled will always serve to keep them behind in the HIV as they can't even access viral load monitoring."

----Online survey respondent, Kenya, community sector

"Early (teenage) marriages for girls lead to inability to get an education and, as a rule, learn more about HIV prevention and the system of care. Weak prevention of vertical transmission among women who use drugs, reinforced by stigma and violence, leads to the fact that they have three times higher rate of vertical transmission."

-Interviewee from eastern Europe and central Asia, community sector

"Women living with and vulnerable to HIV particularly women of transgender experience, occupy spaces where the impacts of racism, patriarchy, poverty, trauma and HIV intersect. UNAIDS must proactively address the compounding effects of these issues in earnest if they are truly committed to leaving no population behind in the HIV response."

—Naina Khanna, Executive Director, Positive Women's Network, Oakland, United States of America

# Case study 1. Gay and other men who have sex with men in Mexico: Targeted approach to increase HIV testing and linkage to care

Mexico's HIV epidemic is highly concentrated among key populations, with gay and other men who have sex with men among the most affected populations. In studies from 2014, up to 44% of gay and other men who have sex with men were found to be HIV-positive, and the highest concentration of new HIV infection have been occurring among young men between the age of 15–29 years.<sup>15</sup>

There are indications that HIV prevention among gay and other men who have sex with men is weakening in some countries. The NGO *Inspira Cambio* decided in 2013 to shift its HIV prevention strategy and place greater emphasis on increased access to HIV testing. *Inspira Cambio*'s HIV programme with gay and other men who have sex with men was launched initially in Mexico City, Saltillo, Hermosillo and Nogales, with funding primarily from federal and local governments. The strategy has several components:

- Increasing the demand for and access to testing, including by promoting rapid HIV testing and self-testing; screening for syphilis, viral hepatitis and herpes in community centres; promoting social networks; and moving services to places where target populations are more likely to congregate;
- Providing tailored counselling that supports linkage to health services;
- Instituting standards that can ensure that linkage is a personalized process that includes
  offering alternatives depending on the results of an HIV test and each person's needs;
- Continuous collaboration with local and national HIV programmes, with the overarching goal that agreements are reached for the benefit of all MSM, whatever their needs.

The programme has reached some 7,000 gay and other men who have sex with men since its inception. Of those, 330 people were newly diagnosed with HIV and referred to care.

### Missing and left behind: People who are excessively vulnerable

- 27. The majority of consultation respondents to this report replied either "no" or "somewhat" when asked whether the UNAIDS definition of key populations covered all people and populations their organizations support. This suggests that the current definition is not adequate in their contexts, for their families, communities or clients.
- 28. For many respondents, the most important gaps in HIV responses occur among certain subpopulations and other groups that face disproportionate vulnerability and that are socially, economically, politically or geographically isolated. As indicated, such individuals often do not fit the categories specified in the UNAIDS definition. Some experience vulnerabilities that are not captured in the definition, while others, face multiple vulnerabilities that cut across any one specific key population.

### Box 3. Observation: Rethinking what "no one left behind" means

"The definition would vary in different country contexts. In that regard, the definition of "no one being left behind" needs to be all encompassing. Some extra focus on the groups who are recorded as being at higher risk. However, if we take our eye off a certain demographic, that demographic might grow [...] There is much more to HIV than access to medications."

-Online survey respondent, Asia-Pacific, community sector

"Young people below the age of 35 represent more than 65% of Africa's population. This offers the continent with a unique opportunity to leverage its economic, social and political development. Which is why adolescent girls, young women and young people who account for the biggest percentage of new HIV infections in Sub Saharan Africa should be a key population regardless of their backgrounds, social lives, sexuality, culture, economic status, religious affiliation and education."

"In my reporting, I have found that identifying and learning about the hidden and discounted epidemics, like ours among Black gay, bisexual men and transgender women across America and especially those in the southern US, is imperative and demands attention and resources."

—Linda Villarosa, journalist and professor, City University of New York, United States of America

- 29. This underscores the need to apply the perspective of intersectionality to the "left behind" concept. According to one interpretation, "*acknowledging the existence of multiple intersecting identities is an initial step in understanding the complexities of health disparities for populations from multiple historically oppressed groups.*"<sup>16</sup> Effectively identifying and responding to the HIV and broader health and development needs of those who are disproportionately vulnerable therefore requires seeing their lives as being "cut across these different realms of experiences".<sup>17</sup>
- 30. In practice, for example, this would mean finding ways to support and bring into care and services young, African-American gay and other men who have sex with men in rural parts of the south in the United States, or indigenous female sex workers who use drugs in India. It would mean recognizing the devastating health and social realities which such populations experience: "Substance use, particularly injection drug use, is strongly associated with HIV infection among Indigenous youth in Canada, where they are often overrepresented among youth who inject drugs in large urban centres."<sup>18</sup> It would also mean acknowledging that many people with multiple vulnerabilities and risk factors, some associated with their gender identity or sexual orientation and expression, can find that their needs are not recognized and addressed. For example, a transgender sex worker might find that services geared for sex workers do not match their realities and needs. Intersecting identities therefore can deepen marginalization.
- 31. These populations and subpopulations differ, as do their needs and the reasons why they tend be "missing" in HIV responses. Yet they are also linked in many respects and tend to bear major health and social burdens. Yet they often are ignored or neglected in HIV and health programmes.
- 32. Reducing the vulnerability of such individuals and communities—and increasing equity– -can only be achieved through universal access to health and enhanced service coverage that reaches the people who are hidden within the current, broader definition of key populations. This can take us beyond the limited 90–90–90 vision toward the goal of 100% coverage.

### The 10–10–10: Who are those left behind?

33. Along with the growing prominence of the 90–90–90 targets and the progress towards reaching them, there is an increasing recognition of the need for an adequate emphasis on prevention and on *universal coverage* for every population, community, and individual. Is it conceivable that countries could reach the 90–90–90 targets while leave entire (sub)-populations or communities behind:

"Sex workers' vulnerability to being left behind depends on the context (legal frameworks, existing anti-prostitution and anti-trafficking policies, implementation strategies, etc.) and varies across the European region. Male and trans sex workers are particularly invisible in the East and Central Asia. In Central and Western Europe, [it is] undocumented migrant sex workers. Generally, sex workers who use drugs are more vulnerable in all settings." — Key population network in Europe

34. Two important points should be kept in mind. The first relates to the inadequate coverage of services among the "classical" key populations—gay and other men who have sex with men, female sex workers, people who inject drugs, transgender persons etc. Due to punitive laws, stigma and other factors, programmes fail to reach these populations even though the programmes may be serving the wider society. The second issue is the reluctance or incapacity of governments to take the necessary steps to reach these populations with the services they need:

"Drug use and sex work are still criminalized, so the legal context and budgets are completely missing. Attitudes of health-care providers are very discriminating and stigmatizing against key populations. There is a general lack of information on treatment and there is a lot of misinformation about treatment including side-effects etc., which causes resistance to accessing treatment." — International network working in the eastern Europe and central Asia region

- 35. Annex 1 contains information about individuals, populations, sub-populations and communities who were identified by consultation respondents as being ignored, highly vulnerable and left behind in their own context. The Annex highlights the importance of intersectionality and context in relation to HIV vulnerability and being "left behind". Responses from every region and grouping point to two important patterns: the evidence of intersectionality across various populations and sub-populations (e.g. sex workers who use drugs), and the frequent omission in definitions of key populations of migrants, indigenous people, people living in rural areas and people living in poverty, covering hundreds of million individuals globally.
- 36. Nearly half of respondents mentioned migrants, and used the term to refer to people migrating within countries or beyond country borders, and to people engaged in both regular and irregular migration. Migration creates or increases people's vulnerability due to the structural obstacles they face in accessing HIV services, and the stigma and discrimination they experience in health-care settings. This vulnerability is aggravated in the case of undocumented migrants who have to survive outside the "system" and who having limited or no access to formal services. The lack of data on sub-populations within migrant populations has been noted in academic publications.<sup>19</sup>
- 37. Subsets of migrants mentioned as being in vulnerable situations to HIV in a range of other different contexts included migrant sex workers (men, women and transgender) and single male migrants (as per several India respondents).
- 38. Several respondents mentioned indigenous peoples. The term has different definitions, but generally refers to tribal minorities (e.g. in India) and groups who were native to a region or country before the arrival of a different group or groups who then became politically, socially, economically and culturally dominant. Indigenous peoples often are culturally and socially marginalized, and their specific worldviews and social systems are seldom recognized in health strategies and engagements. Their specific circumstances can make it difficult to develop and implement programmes that meet their needs. The default response in some countries is neglect or "lip-service".
- 39. A 2015 study noted the disproportionate HIV vulnerability experienced by indigenous peoples in Canada, for example: "Indigenous peoples make up 4.3% of the Canadian population yet accounted for 12.2 % of new HIV infections and 18.8 % of reported AIDS cases in 2011 [...] And in Canada, indigenous peoples' HIV diagnosis rate per 100 000 is 179.2, compared with 29.2 among non-indigenous people."<sup>20</sup>
- 40. Also frequently mentioned in responses were young people—usually in generalized terms, though sometimes more specifically, such as "young people among affected populations":

"Sex workers are also excluded mainly due to legal reasons from the planning of the programmes addressing sex workers [...] migrant and young sex worker: complete absence of adequate services, or recognition in policy documents/strategies [...] it is difficult to work on legal change when you yourself is criminalized and stigmatized." — Key populations network in Europe

41. The findings described in Annex 1 also show respondents' priorities regarding other forms intersectionality. Many mentioned homelessness or a variation (e.g. street children), and people living with disabilities, people who are incarcerated and people co-infected with TB. Several respondents also identified as vulnerable groups and communities that are not commonly considered in relation to HIV, such as religious leaders, cattle nomads, people with mental disabilities, and "Spanish-monolingual Hispanics" (from a North American respondent). Such unique contributions provide further proof of the diversity of HIV vulnerability and respondents' realities around the world.

# Case study 2: Lesbian, gay, bisexual and transgender persons in Namibia—Reaching people outside the main cities and town

By expanding its services outside the Namibian capital and coastal towns, Out-Right Namibia has been able to find, document and offer services to victims of homophobic bias and ill treatment. This has been difficult due to Namibia's large but sparsely populated territory, which makes working outside the capital a costly endeavour (especially with resources for civil society groups having dwindled after Namibia was classified as an "uppermiddle-income" country). Out-Right Namibia's efforts are important because some of the people who need the organization's help the most are living in smaller rural or peri-urban towns.

Out-Right Namibia's expansion of its human rights documentation project to smaller towns and villages has confirmed the lack of service provision for lesbian, gay, bisexual and transgender people based outside the main urban centres. The personal story of Andreas, related below, underscores the vulnerability and invisibility of gay and other men who have sex with men in rural Namibia.

Andreas [a pseudonym] is an 18-year-old man preparing for his final school exams. He identifies as a gay man and has "come out" at home, with his mother and siblings now aware of his sexual orientation. Andreas initially lived at a hostel because he had to attend high school in another town. He wants to go on to obtain a university degree. However, it was not easy being gay and living in a school hostel.

When Out-Right Namibia made contact with Andreas through its regional community coordinator, he had been evicted from the hostel and was denied further residence after returning late from a visit to his mother one weekend. His mother arranged for him to live with his aunt, who was not as open-minded about his sexual orientation as his mother. Soon it was clear that it would be unworkable for him to remain at his aunt's house.

Faced with a choice of giving up on his secondary school leaving examinations, Andreas and his mother contacted Out-Right Namibia. The organization had recently started a service that tracks, documents and responds to violations of Lesbian, gay, bisexual and transgender rights in southern Africa, via a regional Global Fund project known as ReACT. Out-Right Namibia was able to assist Andreas by arranging suitable accommodation for him so he could complete his exams and hopefully achieve university entrance grades.

### III. WE KNOW WHY EXTREME AND DISPROPORTIONATE VULNERABILITY EXISTS--YET IT CONTINUES TO OCCUR

- 42. Why are groups or populations "left behind"? The answers vary, but there are many common themes, including social, cultural, economic, political and legal stigma and discrimination; human rights violations; and poverty. Many respondents also referred to "conservative ideology", either across society as a whole or dominant within some governments, and fundamentalist religious movements etc.
- 43. Other reasons were also cited, including:
  - Lack of specific or targeted strategies or support to engage the population(s)
  - Lack of support for population-driven responses that take a "nothing about us without us" approach, including the Greater Involvement of People living with AIDS (GIPA) principle;
  - Wilful ignorance about the population(s) by governments and/or other providers of services and assistance—for example, by not including them in national strategies or programmes—due to stigma, cultural and economic barriers, and legal obstacles such as the criminalization of key populations, HIV-criminalization or other legislation that discriminate against people living with HIV and other key populations.;
  - Deliberate or inadvertent lack of prioritization by programme implementers and other service providers in regard to HIV and broader health and development issues;
  - Lack of political will to support such population(s);
  - Lack of funding for CBOs that work with the most vulnerable populations; and
  - Negative influence of some religious groups (a factor mentioned frequently by Spanish-language interviewees and respondents to the online survey).
- 44. In addition, some respondents mentioned:
  - Political and economic crises which have resulted in reduced support for health and socioeconomic services (such as the situation in Brazil in recent years);
  - Lack of targeted HIV information, education and communications materials; and
  - Social and gender norms.
- 45. Groups are also left behind due to a lack of data for many groups of people who are disproportionately vulnerable to HIV. Too little is known about how many people are at risk, why they are at risk, and how those barriers can be overcome most effectively. Data that do exist are often not disaggregated (e.g. by age, sex or the type of specific vulnerability) and therefore are of limited use for designing targeted interventions and programmes. As one respondent from the Asia–Pacific region framed it: *"If we don't disaggregate key populations by age, the adolescent and young key populations will always be left behind, as they are not always able to access the available services for key populations due to legal and cultural impediments."* Another respondent from the IHBSS<sup>21</sup> here in the Philippines, the demographic questionnaires are limited to identify if the respondents are sex workers, MSM, or/and IDU."
- 46. The data challenges are often linked to other gaps that help explain why the most vulnerable people are missed by HIV responses. An online survey respondent from Latin America and the Caribbean summarized some of those difficulties: *"There are limited national policies and strategic plans with objectives, targets and indicators for these populations. Consequently, there is no budget for the implementation of activities [...] Nor are there coordinated actions between HIV programmes and institutions that have*

access to other vulnerable populations such as migrants or indigenous people." Another community sector respondent, from North America, highlighted the lack of engagement: "'Left behind' sounds like it's by mistake. They are not even at the starting line. We don't even go to meet them to talk to them."

47. Respondents agreed that whatever the context, reaching out to and supporting populations with targeted, acceptable HIV services is essential for a successful, sustainable, rights-based response. Many also highlighted a need for reforms or new developments more broadly across a range of critical enablers. Particular focus was placed, in nearly every context, on human rights and legal reform—including legalizing sex work, decriminalizing same-sex relationships, eliminating restrictions on access to opioid substitution therapy, eliminating female genital mutilation and gender-based violence, and providing comprehensive sexuality education, especially for adolescents and young people.

# Box 4. Reaching those "left behind": Different barriers in different contexts

"Unmet gaps in services include: rights to health are denied so [they] may not have access to doctors, treatment, culturally safe health care services, services [...] provided in appropriate languages, [or] info presented to them in a way that they can understand it. When rights are violated or when punitive laws are enforced upon a person with no legal status, they have little access to legal counsel, but their safety could be compromised and they could be apprehended."

-Online survey respondent from North America, community sector

"In Russia, only a handful of the key groups [...] as well as sub-groups [...] are covered by HIV responses. (There are no internationally recognized methods of prevention supported to reach all key population groups in Russian—harm reduction, outreach work, needle and syringe exchange programmes, opioid substitution therapy, etc.)."

-Interviewee from eastern Europe and central Asia, community sector

"Children aged 6–14 years are missed and left behind. There are projects for (E)PMTCT, under-5 vaccinations and then from 6–14 years, no one is caring and we give emphasis to sexual modes [...] we should invest in school-based programmes to reach them and community programmes that target HPV vaccinations and cancer screening integrated with HIV. In addition, we should emphasise not only girls and young women, but boys and young men too." —Online survey respondent from Zimbabwe

"The political clout and sway of abolitionist thinking on sex work has meant policies and programmes are being developed and funding that are not rightsbased and thus perpetuate stigma towards sex workers. This deters sex workers from accessing services and therefore sex workers, generally, are left behind."

-Interviewee from eastern Europe and central Asia, community sector

"The current Philippine AIDS law allows young people under 18 from accessing HIV testing and other related services only when parental or guardian consent is presented, making it difficult for members of YKPs [young *key populations] to access HIV-related services."* —Focus group participant from Asia-Pacific, community sector

"The real problems are not being addressed such as poverty; barriers to access to services; violence; weak systems; inadequate services." —Interviewee from Latin America and the Caribbean, community sector

"Uganda can't reach those 90–90–90 treatment targets without addressing the issue of HIV drug resistance. My treatment centre alone has 380 people who are failing on second line yet there are no third-line alternatives. —Focus group participant, Uganda

"In Jamaica and the Caribbean [...] issues of poverty and gender-based violence and violence against children, including child abuse; stigma and discrimination affect intervention in HIV and contribute in people being left behind in the response."

-Interviewee from Latin America and the Caribbean, civil society sector

"Address the populations likely to be ignored by governments in the 90–90–90 treatment targets, invest in inclusive community-led initiatives, channel resources where they are most needed, simplify technical documents for comprehension by communities and governments to improve legal environments, refocus the engagement of PLHIV communities, interrogate new infections in young people generally."

---Focus group participant, AmSHER, South Africa

"It is difficult to make interventions with minors although they have an active sex life. There are challenges for access to ART or other issues [...] Many sex workers are foreigners and sex work is the only option. But many of them live in the street and there is little connection to support services." —Online survey respondent from Latin America and the Caribbean.

community sector [translated from Spanish]

# Case study 3. Key populations in India—Strengthening community voices and increasing visibility

India's National AIDS Control Organization has not been very successful in reaching certain key and vulnerable populations, such as gay and other men who have sex with men, transgender persons and *hijras*. Among the reasons is a lack of understanding and community responsive programmes, and a lack of trust in community organizations.

In response, communities and key populations decided to act. One example was Pehchan, a five-year (2010–2015) project funded by the Global Fund to build capacity, advocate for policy changes to reduce barriers to service access, mitigate violence, provide community-specific services, and strengthen interventions for vulnerable groups in 18 Indian states. The India HIV/AIDS Alliance implemented the programme in partnership with four civil society partners with roots in the targeted communities. Pehchan also carried out community systems strengthening by using the following approaches;

• *Community consultations* to inform programme design, planning, implementation, monitoring, dissemination and impact assessment.

- Community strengthening, which included multiple trainings for gay and other men who have sex with men, transgender and *hijra* community members at grassroots level on issues such as sexuality, gender and identity; safe sex; human rights and law related to homosexuality; community preparedness and more.
- *Mobilization through advocacy* events aimed at increasing visibility and creating platforms for empowerment. For example, national and state-level gatherings of *hijra* were held annually to discuss and promote desirable policy changes.
- Community governance, which emphasized arrangements that shared ownership with elected community members who were not part of programme staff. This helped promote leadership within the communities and ensured that quality services were designed and implemented.
- Employment for gay and other men who have sex with men, transgender people and hijras in key positions. This was achieved by drawing 90% of Pehchan staff from communities that traditionally were underemployed due to stigma, discrimination and a lack of opportunities. Almost 1,900 community staff members trained under Pehchan now have skills to contribute to future National AIDS Control Programme work.

Pehchan helped strengthen 200 CBOs and reached more than 450 000 members of the three priority populations during its five-year existence. Of those, more than 230 000 people took an HIV test and received their results, and almost 2,000 people were linked to treatment centres and initiated antiretroviral therapy. For the first time, female partners of community members were confidentially referred to sexual and reproductive health and rights services.

In addition, strengthened community mobilization strategies, events and advocacy initiatives led to more accurate size estimates of the communities. After Pehchan, the National AIDS Control Programme's estimations for at-risk gay and other men who have sex with men, transgender individuals and *hijra* nearly doubled (to 450 000) which resulted in an increased number of interventions and the expansion of health services in remote districts.

# IV. TURNING THE TIDE: WHAT UNAIDS CAN DO—SUGGESTED ROLES AND RESPONSIBILITIES

- 48. The standardized consultation questionnaire included a sub-section on UNAIDS, with some questions focusing on the roles and responsibilities of UNAIDS and how those may be improved. Focus group discussions and individual interviews also elicited appraisals and suggestions.
- 49. Most of the responses acknowledged the importance and additional value of UNAIDS' work. The added value included technical support, especially for strategic information and capacity building. UNAIDS has been effective, for example, in supporting transgender communities and the HIV Bill in India, as well as vital HIV research in Uganda. UNAIDS has consistently produced and shared high-quality materials to assist partners to respond effectively to the epidemic. It was also seen to support partnerships, for example the development of the Religious Group's proposal in Jamaica, an important partnership with faith-based and other organisations for raising awareness about the epidemic. UNAIDS' work is also recognized in Africa for providing support for community systems strengthening and bringing faith-based organizations together.
- 50. UNAIDS has used its convening power to act as a bridge between civil society organizations and governments, drawing them into dialogue and collaboration. However

respondents in some high-income countries, such as the United Kingdom and the United States of America, commented that UNAIDS' actions were not visible. Respondents also noted that country offices were not highly functional in some eastern European and central Asian countries (with Ukraine an exception) and were not responding adequately to communities' needs. According to a respondent noted from an international network in Europe, UNAIDS should "draw attention to the regional issues of eastern Europe and central Asia, especially the issues around harm reduction. UNAIDS should do the political and diplomacy fight in the region, for the region."

### Challenges for the UN

- 51. There were many responses that highlighted overarching problems with the current UNAIDS. Overall, respondents from Asia-Pacific, as well as eastern Europe and central Asia, were the most vocal and specific in this regard. For example, some respondents from the region suggested that UNAIDS is often overly cautious when pushing back against harmful government policies and not advocating more strongly for evidence-based approaches such as decriminalization or harm reduction. Respondents also mentioned that there has been good work done, but there is a large gap in communication between UN offices, communities and their representatives. Sometimes there is also a mismatch between priorities and strategic ways of working. In some countries, UN agencies are the primary recipients of Global Fund resources, which was viewed as unacceptable by some respondents and has created some tensions between the Joint Programme and the communities. A community leader from Asia-Pacific noted that "UNAIDS competes with networks and NGOs when they start implementing service delivery programmes on ground, rather than supporting civil society and communities for their own advocacy."
- 52. Another respondent expressed that UNAIDS is primarily responding to the "epidemiological picture and not the social determinants nor sustainability" of the response. There are many groups who seem not know much about about UNAIDS. For example, a group of transgender men interviewed in India had not heard about UNAIDS; a group of civil society people interviewed in the United Kingdom reported knowing about UNAIDS at a distance, and an individual interviewed in Germany reported being aware of UNAIDS only as regional entity. These individuals and community groups were also not reached by HIV programmes.
- 53. One other set of comments referred to what might be called UNAIDS' rigidity and lack of flexibility in how it measures and evaluates HIV responses and progress, especially at the country level. This approach is sometimes seen as problematic in that it does not allow for flexibility or breadth in terms of what UNAIDS considers "successes". The comment from an online survey respondent in Asia-Pacific was telling: "UNAIDS focuses on absolute numbers, rather than dissecting the strategic information to see the political—i.e. how key populations are being left behind, when we say that we are doing such a great job and looking at figures which show overall national declines in new infections, for example."

### Call for expanded understanding of vulnerability

- 54. "For our part, we work and identify with the concept of vulnerability that goes beyond the notion of risk for key populations. Strategies should be directed towards the reduction of vulnerabilities. Under this concept we see with importance the work with migrants and other populations, rural residents, indigenous people, [people] co-infected with HIV and tuberculosis." Online survey respondent from Latin America and the Caribbean, community sector [translated from Spanish]
- 55. From the surveys and interviews, it was also apparent that there seems to be tension in many countries (as mentioned by Africa and Asia-Pacific interview participants) among and between UNAIDS and the Cosponsors. It was felt that the tension is an outgrowth of competing agenda between government, community and co-sponsors that leads to reduction of credibility and questioning of technical authority.

#### Inclusion and intersectionality: The way towards ending the AIDS epidemic

- 56. Several suggestions came from community, civil society and stakeholders about how and where UNAIDS should focus its attention to ensure that no one is left behind, including those who are currently being left out by the global AIDS response. As a vital organization that leads and oversees the global HIV response and ecosystem, UNAIDS plays a very important role in political advocacy. Through its diplomacy and convening power, UNAIDS can take responsibility for working with governments to assist them and encourage the development of appropriate national and local HIV responses, including and especially, legal and policy reform. UNAIDS can also work with national governments and various bureaus, departments and ministries (for education, social welfare, finance, economic development etc.), and other relevant agencies to integrate HIV into their respective programmes and services.
- 57. There are a few critical areas where UNAIDS needs to immediately refocus its approach to ensure an improved, more inclusive and more efficient global response. One major role UNAIDS has always played, yet can improve on, is that of a mediator or convener between key populations or communities and governments. This is particularly crucial in situations that require urgent attention: for instance, the "war on drugs" in the Philippines and the ongoing health emergency in Venezuela. Without a full understanding of the importance of putting communities and civil society at the centre of the local and national HIV response, UNAIDS and governments will not be able to address the needs of the missing populations and those left behind.
- 58. Respondents also felt that UNAIDS needs to listen more closely and involve key populations, in all their diversity, more meaningfully. UNAIDS should review and consider merging UN priorities with the priorities of communities. It was seen as an important next step for UNAIDS to be more inclusive of the different segments of communities and not only those communities that we traditionally know. It also has to work toward amplifying the voices of communities by providing technical and financial support. As a community organization working on HIV in Europe put it: "*The definition of key populations should include migrants and key populations among migrants, for example migrant gay men and men who have sex with men, migrant young people, etc. and undocumented migrants.*"
- 59. UNAIDS needs to clarify its role as an "honest broker" in bilateral and other donor relations in the country to ensure that no one is left behind, and it needs to "show they can add value". By being active participants in Country Coordinating Mechanisms, PEPFAR COP processes and other donor mechanisms, UNAIDS can ensure more equitable distribution of resources particularly for key population organisations and networks and NGOs.

60. Some of the feedback from interviews point to a clear way forward:

- "Help communities to advocate for smooth transition from donor to state funding, as well as the necessary legislative changes." (Interviewee from eastern Europe and central Asia, community sector)
- "[Provide] more support for key population organizations and not just those under their definition, but at the national level as well, such as young women and girls and women in difficult circumstances." (Interviewee from Latin America and the Caribbean, community sector)
- "UNAIDS is in a unique position to intervene on legal and regulatory barriers to access. They should take a lead on these. Helping governments better allocate their budgets according to their epidemics." (Interviewee from Europe, migrant community sector)
- *"Provide technical assistance to capacitate the communities on how to understand and appreciate the data."* (Interviewee from Asia-Pacific, community sector)
- "Draw attention to the regional issues of from eastern Europe and central Asia, especially the issues around harm reduction. UNAIDS should do the political and diplomacy fight in the region for the region." (Interviewee from international civil society organization working in the from eastern Europe and central Asia region)
- 61. There is a need to improve the governance of the Joint United Nations Team on AIDS at country level to provide flexibilities that can enable it to increase attention on populations that are left behind. The NGO Delegation is concerned that any reduced importance of UNAIDS can lead to reduced focus on HIV. To avoid such an outcome, civil society, communities and UNAIDS must work together in a constructive way. Supporting civil society to participate in Joint Annual Reviews, AIDS Development Partners' Meetings, as well as Joint UN Support for National AIDS Programmes Coordination Committees, could be one way of involving important community and key population actors more closely to ensure that no one is left behind.

### Renewed attention to previous decision points

62. Several PCB decision points presented by the NGO Delegation in recent PCB reports are highly relevant and closely associated with the 2017 report's topic and emphasis. In the Delegation's view, a key factor missing in target evaluation and responses is the lack of follow-through by UNAIDS on some of the critical decision points of the PCB. More extensive and consistent efforts to take actions specified in decision points are needed to successfully address the challenges identified and to ensure that progress toward the 90–90–90 targets takes into account all disproportionately affected populations.

- 63. Among the previous relevant decision points are the following, with emphasis added in italics:
  - a. UNAIDS/PCB (39)/16.23 Issue date: 11 November 2016

*Recognizes* that to Fast-Track the AIDS response and realize their potential towards ending AIDS, community organizations and networks require sufficient financial resources and that UNAIDS estimates that funding for community mobilization should increase threefold from 2016 to 2020; the proportion of services delivered through community channels should rise to 30% by 2030; and investment in social enablers– –including advocacy, political mobilization, law and reform, human rights, public communication and stigma reduction—should account for 6% of global AIDS investments.

b. UNAIDS/PCB (33)/13.16 Issue date: 6 December 2013

> *Call* on UNAIDS, co-sponsors and partners, as a matter of urgent priority Recalling the 26th PCB, *Agenda item 2: Ensuring non-discrimination in responses to HIV; Decision points: 7.3; 7.4; 7.5; 7.6 and 7.7a*; Recalling the 30th PCB: *Thematic Session on Non-Discrimination: Decision point: 6.1a; requests* UNAIDS and Member States *to report* at the 35th PCB on concrete actions (including support to strengthen national capacity, funds disbursed, the development of data, research and evidence, strengthening of enabling environments including reform to punitive laws and policy) taken to *implement expanded programmes to reduce stigma and discrimination against key populations* (including transgender people), *at sufficient scale* to improve the lives of those at risk of infection and people living with HIV.

- 64. These decision points are intended to lead to greater attention and resources towards key and vulnerable populations and their unequal access to HIV treatment, prevention and support. It has been four years since the 2013 NGO Delegation report<sup>22</sup> warned that *"without concerted action and significant change, the latest initiatives and emerging opportunities risk exacerbating, rather than resolving, the 'equity deficit"* negatively affecting these populations. Stronger and more consistent action is needed to address deficits related to data, financing, rights, capacity and technical support.
- 65. The Delegation regularly has articulated its sense of urgency on data gaps and UNAIDS' responsibilities such as provision of strategic information and evidence to all actors, including civil society and communities living with and most impacted by the epidemic. The following passage is drawn from a document released in April 2017, *The UNAIDS we need: Ten key messages from civil society & communities to the Global Review Panel:*<sup>23</sup>

"UNAIDS needs to fully embrace the global data revolution for the HIV response and better utilize non-traditional data sources; getting data back into programming in a more timely fashion; and sharing data more openly and distributing the data widely including to and with civil society. In particular, UNAIDS should also ensure data disaggregation based on economic, age, race, education, gender identity, sexual orientation, geographic location and other status, to guide programming and investments of programs, and for better targeting of those most in need. Interventions with a laser-focus on the locations and populations will deliver greatest impact and catalyze innovation for people who need it most, ensuring no one is left behind."

### **V. RECOMMENDATIONS**

66. The NGO Report indicates that greater monitoring of compliance with HIV, nondiscrimination and human rights agreements signed by Member States is needed, especially in the context of Agenda 2030, which pledges that no one will be left behind. Recognizing the role of communities in reaching populations left behind and recognizing the need to strengthen the participation of civil society organizations, communities and all populations in the design and implementation of AIDS responses, at all levels; recognizing that more information is needed about the people and communities who are being left behind as countries scale up to meet the 90–90–90 targets—as well about the vulnerability, stigmatization, and legal, social, political, health and other barriers they face; recognizing that closely focused interventions will deliver the greatest impact and catalyse innovation for people who need it most, ensuring that no one is left behind.

The NGO Report introduces the following suggestions for decision points:

- 67. *Recalling* decisions from previous PCB meetings<sup>24</sup> and welcoming the upcoming discussion at the 42<sup>nd</sup> PCB meeting on ways to monitor the achievement of the financial-related targets of the 2016 Political Declaration on Ending AIDS, including the *proportion* of services delivered through community channels should rise to 30% by 2030; and investment in social enablers—including advocacy, political mobilization, law and reform, human rights, public communication and stigma reduction—should account for 6% of global AIDS investments.
- 68. Take note of the report.
- 69. *Request* UNAIDS to support Member States, in collaboration with community based organizations and civil society, to monitor and report on progress made on Fast Track targets disaggregated<sup>25</sup> by key population age and gender, including through the Global AIDS Monitoring.
- 70. *Request* UNAIDS and Member States in partnership with civil society organisations to develop and implement country level community-participatory evidence-gathering methodologies to identify barriers and measure the level and quality of access to services for the "left behind populations" who may or may not be sub-sets of the traditional key populations<sup>26</sup> such as, but not limited to, indigenous communities, people living with HIV, migrants, both regular and irregular, and other mobile populations.
- 71. Request UNAIDS to produce an update on the 2014 *Gap report* addressing the needs and priorities of populations identified to be left behind in the current response and report back to the 43<sup>rd</sup> PCB.
- 72. Request the Joint Programme to facilitate partnerships between Member States and community based organizations to help ensure effective action to meet both HIV prevention and treatment needs of communities, in particular for 'left behind populations'.
- 73. Request the Joint Programme to develop, implement and monitor, in partnership with communities, a standardized community engagement strategy with indicators aligned with the UBRAF and disaggregated data<sup>27</sup> to help ensure effective action to meet their HIV prevention and treatment needs.

[End of document]

# ANNEX 1: WHO IS DISPROPORTIONATELY VULNERABLE: DIVERSITY ACROSS REGIONS AND GROUPS

The table below reflects a wide range of verbatim replies to two questionnaire items which requested input on who should be considered to be disproportionately vulnerable—and thus "left behind" or "missing"—in HIV responses. The responses are grouped into nine categories, primarily by global regions. (India is a separate category because of the particularly large number of responses from the country.) The input illustrates the context-specific nature of the issue and the variety of viewpoints.

The inputs are not necessarily backed up with data, and they do not list every population, sub-population and community that is disproportionately vulnerable to HIV in every context. However, the observations have value since they come people working and living in communities where they have close knowledge of HIV-related vulnerabilities and experiences.

Indigenous populations Indigenous women and girls Women and girls of African descent Indigenous transgender people Rural residents Women in rural areas Agricultural workers Mobile populations Migrants Migrants Migrant sex workers Female partners of men who migrate Ethnic minorities Young women and girls Young people Women in violent situations Women in violent situations, women who are victims of violence Housewives Middle- and upper-class/income gay and other men who have sex with men Poor or working class gay and other men who have sex with men Poor or working class gay and other men who have sex with men Older gay and other men who have sex with men and other men who have sex with men Older gay and other men who have sex with men who have sex with men	Latin America and the Caribbean	
Men who get sexual services from Incarcerated populations	Indigenous populationsIndigenous women and girlsWomen and girls of African descentIndigenous transgender peopleRural residentsWomen in rural areasAgricultural workersMobile populationsMigrantsMigrant sex workersFemale partners of men who migrateEthnic minoritiesYoung women and girlsYoung peopleWomen in violent situationsWomen in violent situations, womenwho are victims of violenceHousewivesMiddle- and upper-class/income gay and other men who have sex with menPoor or working class gay and other men who have sex with men and sex workersYoung gay and other men who have sex with men and sex workersOlder gay and other men who have sex with menOlder gay and other men who have sex with menFemale partners of gay and other men	transgender and intersex youth who are bullied Lesbian, gay, bisexual, transgender and intersex people who live in rural areas Lesbian, gay, bisexual, transgender and intersex people "deprived of liberty" Lesbian and bisexual women Bisexual men and adolescents Young lesbians Male sex workers Heterosexual male sex workers Adolescent sex workers Sex workers from ethnic minorities Female transgender sex workers Transgender people Transgender men Women and girls who use drugs Drug users who do not inject drugs Homeless people People co-infected with TB, hepatitis Young people who were vertically infected with HIV People trying to reintegrate into society in post-conflict situations Reclusive people People older than 50 Persons with disabilities Youth with disabilities

transgender people Gay and other men who have sex with men in discordant relationships Gay and other men who have sex with men with disabilities	
India	
Tribal populations	Housewives of migrant labourers
Farmers	Truck drivers
Residents of rural and hilly areas	Young female sex workers
TB patients	Female sex workers and gay and
Partners of people living with HIV	other men who have sex with
People coinfected with HIV and TB	men who are not in "traditional
Adolescents	sites" Female sex workers who use drugs
Key populations in online settings	(but do not inject drugs)
People with risky behaviour and	Regular partners of sex workers
lifestyles	Sex workers from ethnic minorities
People who are invisible but are high risk	Young people who use drugs
Spouses of PLHIV	Women and girls who use drugs
Young people living with and affected	Wives of people who use drugs
by HIV	Spouses of married gay and other
Children living with HIV	men who have sex with men
Orphans and vulnerable children	Gay and other men who have sex with men from lower
Transgender populations	socioeconomic strata
Transgender women	Very poor people
Transgender men	Partners of gay and other men who
Transgender women in rural areas	have sex with men and
hijra	transgender people
Migrants Missing to be available	Females who inject drugs
Migrant labourers	Prisoners, in particular people who use drugs, women, youth and
Single male migrants	transgender people
	Adolescent gay men
	Homeless people
Asia–Pacific and Oceania (excluding Ind	Jia)
Young key populations younger than	Pregnant women
18	Gay men and other men who have
Out-of-school youth	sex with men who use
Sexually active under-age children and	recreational drugs
young people Gang members and clans	Partners of people living with HIV
Migrant workers	People coinfected with TB and/or hepatitis C
Families of migrant workers	Children and adolescents
Migrant workers in the fisheries	Prisoners
industry	Family members who carry the
Sex workers who are migrants	burden for those affected by HIV
Seafarers	People living in rural areas
Children of parents who are living with	Women and girls

HIV	Housewives
Homeless people	Non-venue sex workers
Freelance sex workers	Male sex workers
People with disabilities	Women who use injecting drugs
Indigenous peoples	Urban gay and other men who have
Indigenous peoples living in colonised	sex with men populations
contexts	Gay and other men who have sex
People with disabilities	with men who identify as
Muslim gay and other men who have	"straight"
sex with men and who liv in Muslim-	Adolescents
majority countries	Transgender community
Eastern and southern Africa	
Migrants	Truck drivers
Migrants in immigration detention	Long-distance drivers
centres	Students in higher levels of learning
Internally displaced populations	Health workers
Young women and adolescent girls	Children of sex workers
Uniformed services (e.g. the military)	Cattle nomads
Widows	Minors
Widows in rural areas	People with mental illnesses
Key populations in rural areas	People who abuse alcohol
Young key populations	Elderly people living with HIV
Homeless people	Intersex people and other gender
Orphans and caretakers	nonconforming persons
Street children	Serodiscordant couples
Young sex workers under 18 years who	Adolescent sex workers
are regarded as children by law	Young people who inject drugs
People living in poverty, slums	Elderly people who look after the
People living with disabilities People coinfected with TB and/or	orphans Sebeelebildren
hepatitis	Schoolchildren
People with mental illnesses	Children in sexual exploitation
People with comorbidities	Adolescent lesbian, gay, bisexual, transgender and intersex
Boda boda men <sup>28</sup>	Adolescent girls in slums
Fisher folks	
West and central Africa	
Migrants	Street/homeless children
Migrant fisher folk, traders, transporters	Young gay and other men who have
Hidden migrant or refugees	sex with men
Rural populations	Male sex workers
Slum dwellers	Adolescent sex workers
Urban slum dwellers	Teenage mothers
Beggars with disabilities	Females who inject drugs
Orphans and vulnerable children	High-profile sex workers
	Children aged 6–14 years

Eastern Europe and central Asia		
Migrants Wives of migrants Internally displaced people Sexual partners of people who use drugs Young girls kidnapped as brides Women and girls in rural areas Women and young girls Youth Girls People with mental disabilities Transgender people Transgender people Transgender people of colour Young transgender people Transgender people Street children	<ul> <li>People with coinfections</li> <li>Women who use drugs</li> <li>Gay and other men who have sex with men and who use drugs</li> <li>Older gay and other men who have sex with men</li> <li>Young gay and other men who have sex with men</li> <li>Older gay and other men who have sex with men</li> <li>Older gay and other men who have sex with men</li> <li>Gay and other men who have sex with men and who have mental health issues</li> <li>Gay and other men who have sex with men and who have sex with men who are from small towns and rural areas</li> <li>Migrant gay and other men who have sex with men who are foreign residents</li> <li>Roma members of key populations</li> <li>Adolescents and women affected by military conflict</li> <li>Military staff and their partners</li> </ul>	
Western Europe		
Migrants and other mobile populations Undocumented migrants Gay and other men who have sex with men who are migrants Migrant trans persons Residents of rural areas Homeless people Young people People living in poverty	Trans populations Trans sex workers People living with hepatitis C Deaf people Male drug users who have sex for money Chemsexers (i.e. people who have sex while under the influence of drugs such as methamphetamine)	
North America		

oners ck & Latino gay men (ages 18- g) no immigrant gay and other men who have sex with men (aged 8–30 years) ck gay and other men who have ex with men, especially those ving in the south of the USA lescent African-American gay and other men who have sex with nen nish-monolingual Hispanics banic/Latino population can American population can-American women and atinas in general ple living with HIV who are aging ple over 50 erosexual men and women ple with disabilities ple with substance use issues ple of colour across the key opulations ple living in poverty ple with inadequate education ple living in stigmatized ommunities nily members of people living with HIV -English speakers ple who do not have medical
nsurance
ns
neless people genous peoples ple living in complex settings humanitarian settings), including nigrants, refugees, people living n war areas men and girls living in certain egions idents of areas with weak health systems ple older than 50 ulations in crisis ple who use drugs in prisons lescents from key populations ider non-conforming youth nas and Latinos who are gay or
les ide

### **ANNEX 2: ACKNOWLEDGEMENTS AND PARTICIPANTS**

The NGO Delegation to the PCB extends its appreciation and gratitude to all the individuals and organizations who contributed their time, experience and insights to this report. They include the 171 respondents in the online survey, as well as the participants of the interviews and focus group discussions listed below:

#### Interviews and focus group discussions

- Action for Health Initiatives (ACHIEVE), Inc., Junelyn R Tabelin, project coordinator, the Philippines
- Action for Health Initiatives (ACHIEVE), Inc., Jay Arian C Caparida, project coordinator, the Philippines
- Action for Health Initiatives (ACHIEVE), Inc., Leslie Arididon-Tolentino, project coordinator, the Philippines
- Action for Health Initiatives (ACHIEVE), Inc., Florence J. Mira, social mobilization officer, the Philippines
- Action for Health Initiatives (ACHIEVE), Inc., Jetro Calaycay, project staff, the Philippines
- Action for Health Initiatives (ACHIEVE), Inc., Easter Sunshine Catedral, advocacy officer, the Philippines
- Action for Health Initiative (ACHIEVE), Inc., anonymous, Media and Communications Officer
- AFEW International, Anke van Dam, executive director, Netherlands
- Africa Advocacy Foundation, Denis Onyango, programmes director, United Kingdom
- African Men for Sexual Health and Rights [AMSHeR], five anonymous respondents, South Africa
- All-Ukrainian Charitable organization "Legalife-Ukraine", Ukraine
- Alliance Against AIDS (no longer active), Rodel Perera, executive director, Belize
- Alliance Global, Ukraine
- Andrey Rylkov Foundation for Health and Social Justice, Russian Federation
- Canadian Association of People Who Use Drugs and Stella By And For Sex Workers, Alexandra de Kiewit, Canada
- Canadian Positive People's Network, Christian Hui, co-founder, Canada
- Collaborative Network of Persons Living with HIV (CNET+), Lizet Aldana, programme coordinator, Belize
- Committee for Accessible AIDS Treatment, Anonymous, Canada
- Person living with HIV, anonymous, India
- Epidemiologist, civil society organization, Tajikistan
- Eurasian Women's Network on AIDS, Ukraine
- Fidokor (ICSO), two anonymous respondents, Tajikistan
- Forum of people using drugs, Russian Federation
- Gestos—HIV, Communication & Gender, anonymous, Brazil
- Gujarat State Network of People Living with HIV, anonymous, India
- Guyana Trans United, Devanand Milton, president, Guyana
- International Committee on the Rights of Sex Workers in Europe (ICRSE), Luka Stevenson, United Kingdom
- HPLGBT, Ukraine
- International HIV Partnerships, ReShape, Network of Low HIV-Prevalence Countries in Central and Southeast Europe, Ben Collins, director (IHP), United Kingdom
- Jamaica Council of Churches / Religious Groups Steering Committee, Canon Garth Minott, programme coordinator, Jamaica
- KIYANKA+, Ukraine
- MadhyaPradesh Network of People Living with HIV, anonymous, India
- Mizoram Network of Positive Women, anonymous, India

- Molodezhnyi vzglyad, Tajikistan
- National Coalition of People Living HIV in India, anonymous, India
- Network of Maharashtra People Living with HIV, anonymous, India
- Peer to Peer Uganda, Nakamate Irene, monitoring and evaluation officer, Uganda
- Positive Women's Network, anonymous, India
- Rokhi Zindagi, civil society organization, Tajikistan
- Sex Workers Rights Advocacy Network in Central and Eastern Europe and Central Asia (SWAN), Stasa Plecas, executive director, Hungary
- Snid-Dopomoga (social agency), Ukraine
- Tajik Network of Women Living with HIV, Tajikistan
- TWEET TG, ten anonymous respondents, India
- Uganda Network of young people living with HIV, Niwagaba Nicholas, programme director, Uganda
- Uganda Youth Coalition on Adolescent Sexual Reproductive Health Rights and HIV, Allen Kyendikuwa, lead-programmes, Uganda
- UttarPradesh Network of People Living with HIV, anonymous, India
- Vincy CHAP: St. Vincent and the Grenadines Caribbean HIV AIDS Partnership, La Fayette Johnson, member, St Vincent and the Grenadines
- Women's Organisation Network for Human Rights Advocacy, Diana Natukunda, advocacy and communication officer, Uganda

#### Others

- Six respondents from North America from the following types of organizations: community pharmacies, academic research centres, community health centres, AIDS service organizations and pharmaceutical companies;
- Three respondents from international organizations in Asia-Pacific;
- Six respondents from India who are representatives of NGOs that work with sex workers; lesbian, gay, bisexual, transgender and intersex groups; people who inject drugs; young people affected and living with HIV; and people living with HIV. Some of them also work in legal literacy and human rights (Raman Chawla, civil society activist, New Delhi; Dr. Sundar Sundararaman, civil society activist, Chennai; Mona Mishra, civil society activist, New Delhi; Sanghamitra Iyengar, Samraksha, Bangalore; Shyamla Natraj, SIAAP, Chennai; Dr. Ashok Rau, Freedom Foundation, Bangalore).

### **ANNEX 3: ABBREVIATIONS**

AIDS	acquired immune deficiency syndrome
ART	antiretroviral therapy
СВО	community-based organization
Global Fund	Global Fund to fight AIDS, Tuberculosis and Malaria
HIV	human immunodeficiency virus
NGO	non-governmental organization
PCB	Programme Coordinating Board
PHIA	population HIV impact assessment
UBRAF	Unified Budget, Results and Accountability Framework
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization

#### REFERENCES

<sup>1</sup> The 38th PCB DP 5.2, 6.2(b), 6.4 and the 39th PCB DP 8.1; and the 2016 Political Declaration on HIV and AIDS paragraph 63 (a)–(e), which recognizes the mandate of UNAIDS to being accountable to civil society and communities; and recalling the UNAIDS/PCB (39)/16.23 which recognizes that funding for community mobilization should increase threefold from 2016 to 2020 and that the proportion of services delivered through community channels should rise to 30% by 2030; and investment in social enablers – including advocacy, political mobilization, law and reform, human rights, public communication and stigma reduction – should account for 6% of global AIDS investments.

<sup>2</sup> UNAIDS should ensure data disaggregation based on economic, age, race, education, gender identity, sexual orientation, geographic location and other status, to guide programming and investments of programs, and for better targeting of those most in need. (Ten Key Messages from CSO to the GRP, 2017)

<sup>3</sup> Such as for example sex workers who use drugs, women living with AIDS in rural areas, migrants, trans, gays and bisexual indigenous people, people living in rural areas, people living in poverty.

<sup>4</sup> UNAIDS should ensure data disaggregation based on economic, age, race, education, gender identity, sexual orientation, geographic location and other status, to guide programming and investments of programs, and for better targeting of those most in need. (Ten Key Messages from CSO to the GRP, 2017)

<sup>5</sup> Ending AIDS: Progress towards the 90-90-90 targets. Geneva: Joint UN Programme on HIV/AIDS; 2017 (www.unaids.org/en/resources/campaigns/globalAIDSupdate2017).

<sup>6</sup> Ending AIDS: Progress towards the 90-90-90 targets. Geneva: Joint UN Programme on HIV/AIDS; 2017 (www.unaids.org/en/resources/campaigns/globalAIDSupdate2017).

<sup>7</sup> In addition to Botswana, the following six countries reportedly "had already achieved or exceeded this level of viral suppression by 2016": Cambodia, Denmark, Iceland, Singapore, Sweden and the United Kingdom of Great Britain and Northern Ireland. In addition to Swaziland, the following 10 countries were listed as being "near this threshold": Australia, Belgium, France, Germany, Italy, Kuwait, Luxembourg, Netherlands, Spain and Switzerland.

<sup>8</sup> http://phia.icap.columbia.edu/press-release-five-african-countries-approach-control-of-their-hiv-epidemics-as-u-s-government-launches-bold-strategy-to-accelerate-progress/

<sup>9</sup> Carter M. "Many Western European countries close to achieving UNAIDS 90–90–90 targets" Aidsmap, 25 June 2017 (www.aidsmap.com/Many-Western-European-countries-close-to-achieving-UNAIDS-90-90-90-targets/page/3150969/).

<sup>10</sup> www.unaids.org/en/resources/presscentre/featurestories/2016/november/20161121\_keypops

<sup>11</sup> Ending AIDS: Progress towards the 90-90-90 targets. Geneva: Joint UN Programme on HIV/AIDS; 2017 (www.unaids.org/en/resources/campaigns/globalAIDSupdate2017).

<sup>12</sup> Kerr T et al. The impact of compulsory drug detention exposure on the avoidance of healthcare among injection drug users in Thailand. Int J Drug Policy. 2014;25(1):171–4.

<sup>13</sup> www.aidspan.org/node/4242

<sup>14</sup> Prevention gap report. Geneva: UNAIDS; 2016 (www.unaids.org/en/resources/documents/2016/prevention-gap).

<sup>15</sup> Centro Nacional para la prevención y el control del VIH y el sida (Censida), 2016 (www.gob.mx/censida/articulos/dia-mundial-del-sida-mexico-2016-85309?idiom=es).

<sup>16</sup> Bowleg L. The problem with the phrase women and minorities: intersectionality—an important theoretical framework for public health. Am J Public Health. 2012;102(7):1267–1273.

<sup>17</sup> Bowleg L. The problem with the phrase women and minorities: intersectionality—an important theoretical framework for public health. Am J Public Health. 2012;102(7):1267–1273.

<sup>18</sup> Negin J et al. HIV among indigenous peoples: a review of the literature on HIV-related behaviour since the beginning of the epidemic. *AIDS Behav*. 2015;19(9):1720–1734.

<sup>19</sup> Weine S, Kashuba A. Labor migration and HIV risk: a systematic review of the literature. *AIDS Behav*. 2012; 16(6):1605–1621.

<sup>20</sup> Negin J et al. HIV among indigenous peoples: a review of the literature on HIV-related behaviour since the beginning of the epidemic. *AIDS Behav*. 2015;19(9):1720–1734.

<sup>21</sup> Integrated HIV Behavioural and Serologic Surveillance

22

http://files.unaids.org/en/media/unaids/contentassets/documents/pcb/2013/pcb33/agendaitems/20131206\_PCB-NGO-report.pdf.

<sup>23</sup> The full text of the document is available at www.eatg.org/news/10-key-messages-from-civil-society-and-communities-to-the-unaids-global-review-panel/.

<sup>24</sup> The 38th PCB DP 5.2, 6.2(b), 6.4 and the 39th PCB DP 8.1; and the 2016 Political Declaration on HIV and AIDS paragraph 63 (a)–(e), which recognizes the mandate of UNAIDS to being accountable to civil society and communities; and recalling the UNAIDS/PCB (39)/16.23 which recognizes that funding for community

mobilization should increase threefold from 2016 to 2020 and that the proportion of services delivered through community channels should rise to 30% by 2030; and investment in social enablers – including advocacy, political mobilization, law and reform, human rights, public communication and stigma reduction – should account for 6% of global AIDS investments.

<sup>25</sup> UNAIDS should ensure data disaggregation based on economic, age, race, education, gender identity, sexual orientation, geographic location and other status, to guide programming and investments of programs, and for better targeting of those most in need. (Ten Key Messages from CSO to the GRP, 2017)

<sup>26</sup> Such as for example sex workers who use drugs, women living with AIDS in rural areas, migrants, trans, gays and bisexual indigenous people, people living in rural areas, people living in poverty.

<sup>27</sup> UNAIDS should ensure data disaggregation based on economic, age, race, education, gender identity, sexual orientation, geographic location and other status, to guide programming and investments of programs, and for better targeting of those most in need. (Ten Key Messages from CSO to the GRP, 2017)

<sup>28</sup> A Ugandan term for motorcycle riders who transport people.