POSITION PAPERS

Stigma and Discrimination
Youth Participation
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DECLARATION

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Persons living with HIV and inadequately served populations constantly face barriers to accessing quality health services, commodities and information.

These individuals continue to face stigma, discrimination, criminalization and ill-treatment based on their actual or perceived health status, race, socio-economic status, age, sex, sexual orientation or gender identity and expression. Stigma can be understood as “a process that begins when a specific trait or group is labeled and linked to negative stereotypes, leading to status loss and discrimination for those carrying the trait”.

“HIV related stigma and discrimination is a harmful social phenomenon that perpetuates negative feelings.”

1UNAIDS, Agenda for zero discrimination in health care (2016)
Stigmatization is underpinned by many factors including the lack of understanding of the particular circumstance, misconceptions and preconceived notions from an uninformed position, irresponsible reporting alongside media interference and general prejudices. It can affect the well-being of individuals in a multiplicity of ways. It is also a concept deeply embedded in language. Since the onset of the epidemic, metaphors associated with HIV such as death, guilt, horror have sought to legitimize the stigmatization associated with the virus. When stigma is acted upon, the result is discrimination. The term discrimination can be understood to mean “any act or behavior that has the intention or effect of impairing the enjoyment of fundamental human rights by all people on equal footing.”

HIV related stigma and discrimination is a harmful social phenomenon that perpetuates negative feelings, attitudes and sometimes violent behavior towards people living with and affected by HIV which results in them being treated unfairly and unjustly. Stigma and discrimination are rarely linked to one characteristic of a person. It is often fueled by multiple factors, referred to as intersectional or multiple discrimination. Individuals belonging to particular groups such as, but not limited to, adolescents, LGBTI persons and PLHIV, are more likely to be disproportionately affected by intersectional discrimination in the context of their sexual and reproductive health. Interplay between different forms of discrimination has a major role in determining health outcomes and broader opportunities.

The irrational fears and negative attitudes and judgement, misinformation and prejudice towards individuals from key population groups have persisted despite years of public educational campaigns and remains a significant obstacle to the fulfilment of the right to access health care. Stigma and discrimination in health care settings over the years have broadly

“Programs aimed at reducing stigma and discrimination against PLHIV should address the actionable causes”
undermined access to prevention, treatment and care services and the quality of health care delivered to members of key population groups. It has also significantly undermined a community’s ability to protect themselves. Stigma and discrimination towards such groups have also been directly and indirectly reinforced by laws, policies, practices and other structural barriers, exploitation and a climate of fear that hinders efforts to provide prevention methods and services at sufficient levels of coverage.

Health facilities, goods, information and services related to sexual and reproductive health (SRH) should be accessible to all individuals and groups free from discrimination and other barriers. Measures to guarantee non-discrimination and substantive equality should be cognizant of and seek to overcome the often-exacerbated impact that intersectional discrimination has on the realization of the right to SRH. The 2016 UN Political Declaration on HIV and AIDS reinforces the commitment of member states to eliminate barriers, including stigma and discrimination, in health care settings, to ensure universal access to comprehensive HIV diagnostics, prevention, treatment, care and support for people living with, at risk of and affected by HIV, children, adolescents, young people, women and other vulnerable populations. Visibility and openness about the AIDS epidemic are prerequisites for successful mobilization of government, communities and individuals to respond to the epidemic.

By focusing on instituting a people centered approach, services would be able to build trust between health care workers and beneficiaries whilst improving health outcomes and increasing confidence in service providers. A people-centered approach should also be rights-based which upholds the tenets of inclusivity, non-discrimination and respect and looks at the particular needs and circumstances of affected populations and at-risk groups. Programs aimed at reducing stigma and discrimination against PLHIV should address the actionable causes and seek to empower these individuals. Two critical steps in mitigating this issue is through the sensitization of law makers and law enforcement agents about the importance of the law in the HIV response and its role in creating an enabling environment and through the sensitization and continuous education of health care professionals on the importance of valuing human rights and medical ethics as a means of reducing stigmatizing attitudes in health care.
Key stakeholders and actors should also seek to facilitate unrestricted access to justice and redress in cases of discrimination. Alongside this, it is essential to monitor, reform and establish laws, regulations and policies that support proper access to health services.

It is also important to acknowledge that there are benefits in expanding the capacity of those living with, affected by or at-risk of HIV about human rights and the national and international laws relevant to HIV. This commitment to legal literacy enables groups and individuals to embark on organized evidence-based advocacy as a means of lobbying for specific solutions to combat critical issues. Such programs should focus on providing information on both legal and rights knowledge whilst exploring strategies on how to utilize such information to improve access to health and justice and challenge the barrier that is stigma and discrimination.

\footnote{UNAIDS, Confronting Discrimination: Overcoming HIV related stigma and discrimination in health care settings and beyond, (2017)}
\footnote{Committee on Economic, Social and Cultural Rights, Right to Sexual and Reproductive Health, General Comment No. 22 (2016)}
\footnote{Ibid (2016)}
\footnote{UN General Assembly, Political Declaration on HIV and AIDS, (2016) para 62(j) A/RES/70/266}
Jamaican young people, between the ages of 15 and 29, are at the core of national development and regarded as the drivers of change. However, the perceptions around the rates and levels of investment in their growth and advancement have unveiled a troubling reality. A survey conducted with approximately 3024 persons across Jamaica by Respect Jamaica in collaboration with UNICEF Jamaica revealed that 92% of persons surveyed felt that the government does not sufficiently or adequately take the views of young people into account when making decisions that concern them. 95% of the sample felt that the government does not fully engage or empower young people and 81% also felt that they would consider migration to have better opportunities in future.

Youth Participation refers to the process of involving young people in the decisions and institutions that affect their environment.
A baseline study of 3668 adolescents and young adults between the ages of 14 and 25 conducted by Talk Up Youth disclosed that more than 50% of those surveyed felt that government officials are not responsive to the needs of young people. With youth at the core of the 2030 sustainability goals, such statistics reflects a serious setback and requires intervention in all forms and at all levels. Contrary to position that young people are voiceless in a Jamaican society, opposition has advanced several arguments in response to such assertions. The general sentiment that young people have no interest in participating in the affairs of the country has taken its place at the fore of any counter-argument and has often qualified all ancillary responses. This perceived lack of interest supports the notion that existing youth sentiment around youth engagement and participation is without foundation. Counter-positions have also continued to suggest that the government and relevant stakeholders have provided an enabling environment that facilitates youth participation and provides opportunities for their growth. At the core of such a benefit is also the perception that any perceived hindrance on their development is as a result of the lack of capacity of young people and their inability to sufficiently take advantage of the opportunities that are consistently presented to them.

Article 12 of the UN Convention on the Rights of the Child, the right to be heard, is recognized as the guiding principle for child and youth participation.
Nevertheless, the perceived lack of interest, is a result of years of constant neglect coupled with limited accountability. Hart’s Ladder of Participation\(^2\) which has been designed to serve as a beginning typology for thinking about youth participation in projects recognizes that there are three levels of non-participation which have been disguised and represented as examples of participation. Manipulation, decoration and tokenism are the three rungs of the ladder which have characterized a significant portion of the experiences faced by young people in their pursuit of opportunities for meaningful engagement. Consulting with young people but disregarding the importance of feedback, utilizing youth without ensuring that they possess sufficient knowledge and crafting the narrative of a young person then ushering them to present it as their own are some of the many examples which classify how youth participation has been approached and why young people believe that it is counter-productive and contrary to their inherent right to participate.

Youth Participation refers to the process of involving young people in the decisions and institutions that affect their environment and their lives in it\(^3\). Article 12 of the UN Convention on the Rights of the Child, the right to be heard, is recognized as the guiding principle for child and youth participation. It states that children shall be guaranteed the right to express their views freely in all matters affecting them and such views must be given due weight in accordance with their age and maturity. The exercise of this right is integral to the process of participation which recognizes that including young people should not only be a momentary act, but the starting point for an intense exchange between them as rights holders and their counterparts, as duty bearers in the development of policies, programmes and measures in all relevant contexts. Youth participation, and its importance, has been emphasized as a means of political and civil engagement through which they are able to adequately negotiate and advocate for the realization of their rights and hold governments accountable\(^4\). Countries across the Caribbean
region are under a legal obligation to provide an environment that enables our youth to exercise this right\(^5\). They are under a responsibility to develop and implement programs that promote meaningful participation in decision-making processes at all levels and in various spaces\(^6\).

The capacity for progress of any society is based on its capacity and ability, amongst other things, to incorporate the contribution and responsibility of youth in the creation of a future\(^7\).

Young people and their imagination, ideals, considerable energies and vision remain an untapped resource that is essential for sustainable development. They are key agents of social change, economic development and technological innovation. Young people, regardless of their geographical location, existing at different stages of their development and managing a plethora of socio-economic realities, aspire to full participation in the life of society. Meaningful youth participation requires that young people have opportunities, capacities and are able to benefit from an enabling environment.

As such, the following recommendations are necessary to the fulfillment of the right to participate:

**#1** Central to working with young people is to create an enabling environment which recognizes their right to participate and the importance of legitimizing their voice. Programmatic work should seek to explore and implement a more inclusive and human rights-based approach when integrating young people in the work that is being done. States are under a legal obligation to facilitate youth participation through consultation processes thereby ensuring their ability to meaningfully contribute to national dialogue on policies, laws and decisions related to them and their development.

**#2** Young people should also be included in all aspects of programmatic work from the design of an initiative/project to its implementation and to the final monitoring and evaluation of all progress and outcomes. In an attempt to ensure continuity and adequate succession planning, young people are to be equipped with the skills, tools and perspectives to navigate national dialogues as a means of effectively transitioning from one generation to the next as society collectively journeys towards achieving the 2030 goals.

**#3** Focus should also be placed on including youth from various sectors of life. As a means of acknowledging that human rights are interdependent, the right to non-discrimination is an inherent right guaranteed by all human rights instruments. Every young person has the right not to be discriminated against in the exercise of his or her rights including the right to be heard/participate. State parties shall take adequate measures to assure to every child the right to freely express his or her views and to have those views duly taken into account without discrimination on the grounds stated in the international instrument.

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1. Respect Jamaica, UNICEF, Youth Survey (2016)
2. Hart Roger, “Children’s Participation: From Tokenism to Citizenship” Innocenti Essays (No. 4) (1992) UNICEF, Italy
3. Checkoway 2011
4. Committee on the Rights of the Child, General Comment No. 20 (2016)
5. Committee on the Rights of the Child, General Comment No. 12 (2009)