

PARTICIPATION SUMMARY



GLOBAL NETWORK OF
YOUNG PEOPLE
LIVING WITH HIV

BACKGROUND ON YOUTH PARTICIPATION

Participation has been a foundation of good development for many years ensuring individuals and communities can access information and influence the decisions that affect their lives. Models of participation have been developed and debated at length but commonly promote the ownership and commitment of communities, and the active participation by local citizens, in programmes and policy development.

More recently there has been growing attention on the engagement of young people in development as a 'right' and as critical to the promotion of active citizenship and participation in society. This summary looks specifically at participation of young people within the HIV response.

Commitment to participation is based on the belief it promotes more sustainable and effective development programmes and is underpinned by the rights of each person to participate and this includes young people.

The interest in the participation of young people was cemented with the establishment of the Convention on the Rights of the Child (CRC) in 1990, now ratified by over 100 nations.

The CRC contains 54 articles with Article 12 of the Convention making the clear call for participation through access to information and freedom of expression supported by Articles 13, 14 and 15.

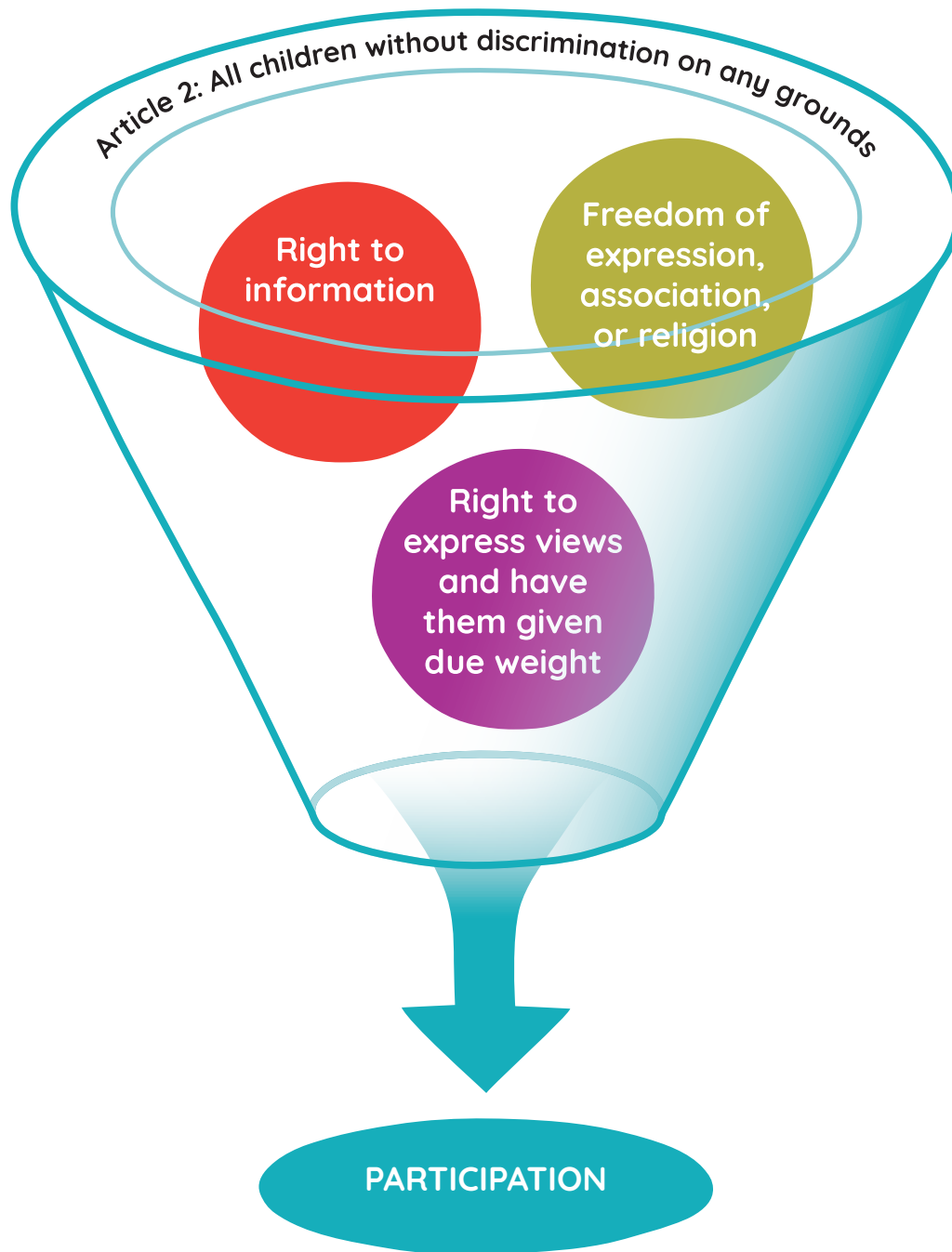
States Parties shall assure to the child who can form his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.

With the adoption of the convention, more was written to support understanding these articles and developing principles for child and youth participation. In 2009 the Committee on the Rights of the Child adopted additional information to support signatories to the CRC on understanding participation and provided nine requirements. It must be **transparent** and **informative**; **voluntary**¹; **respectful**; **relevant**; **child-friendly**; **inclusive**; **supported by training for adults**; **safe and sensitive to risk**; and **accountable**.

Despite these efforts the right of children and young people to be heard is still far from a reality for all and work continues to provide guidance and improve accountability to the articles laid out in the CRC.

¹. non pressured or forced

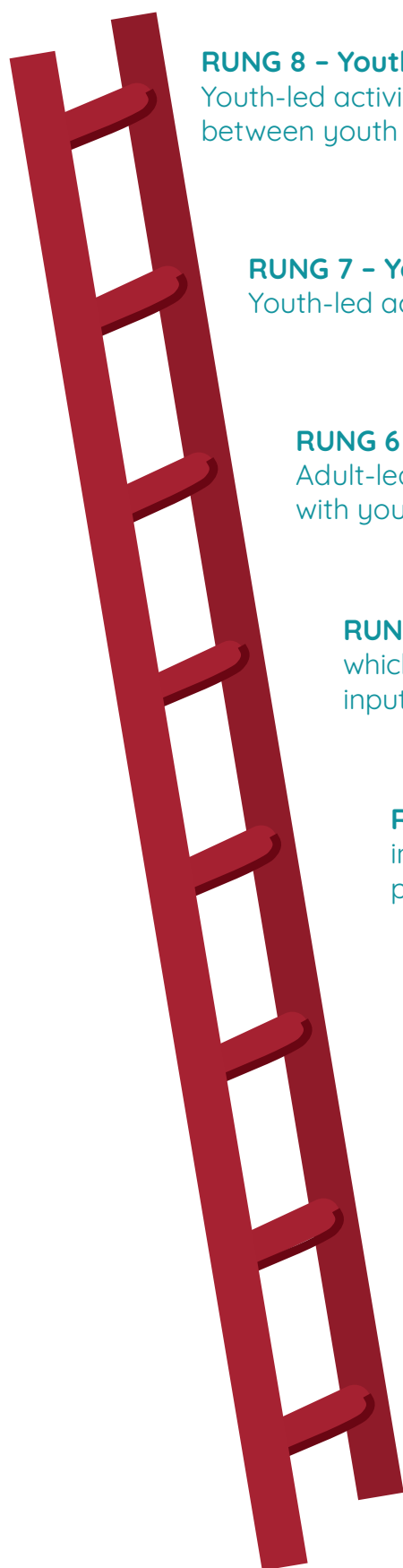
Participation in the context of the CRC²



In 1992 Roger Hart developed the concept of the ladder of participation to help people understand the different levels of participation- engaging young people in a meaningful and ethical way where they share the power and decision making. This model has been adapted by many organisations over the years and still offers an important framework to view participation and a reference for understanding the value greater participation can bring.

². UNICEF 2018 Conceptual Framework for Measuring Outcomes of Adolescent Participation

Roger Hart's Ladder of participation³



RUNG 8 – Youth initiated shared decisions with adults:

Youth-led activities, in which decision making is shared between youth and adults working as equal partners.

RUNG 7 – Youth initiated and directed:

Youth-led activities with little input from adults.

RUNG 6 – Adult initiated shared decisions with youth:

Adult-led activities, in which decision making is shared with youth.

RUNG 5 – Consulted and informed: Adult-led activities, in which youth are consulted and informed about how their input will be used and the outcomes of adult decisions.

RUNG 4 – Assigned, but informed: Adult-led activities, in which youth understand purpose, decision-making process, and have a role.

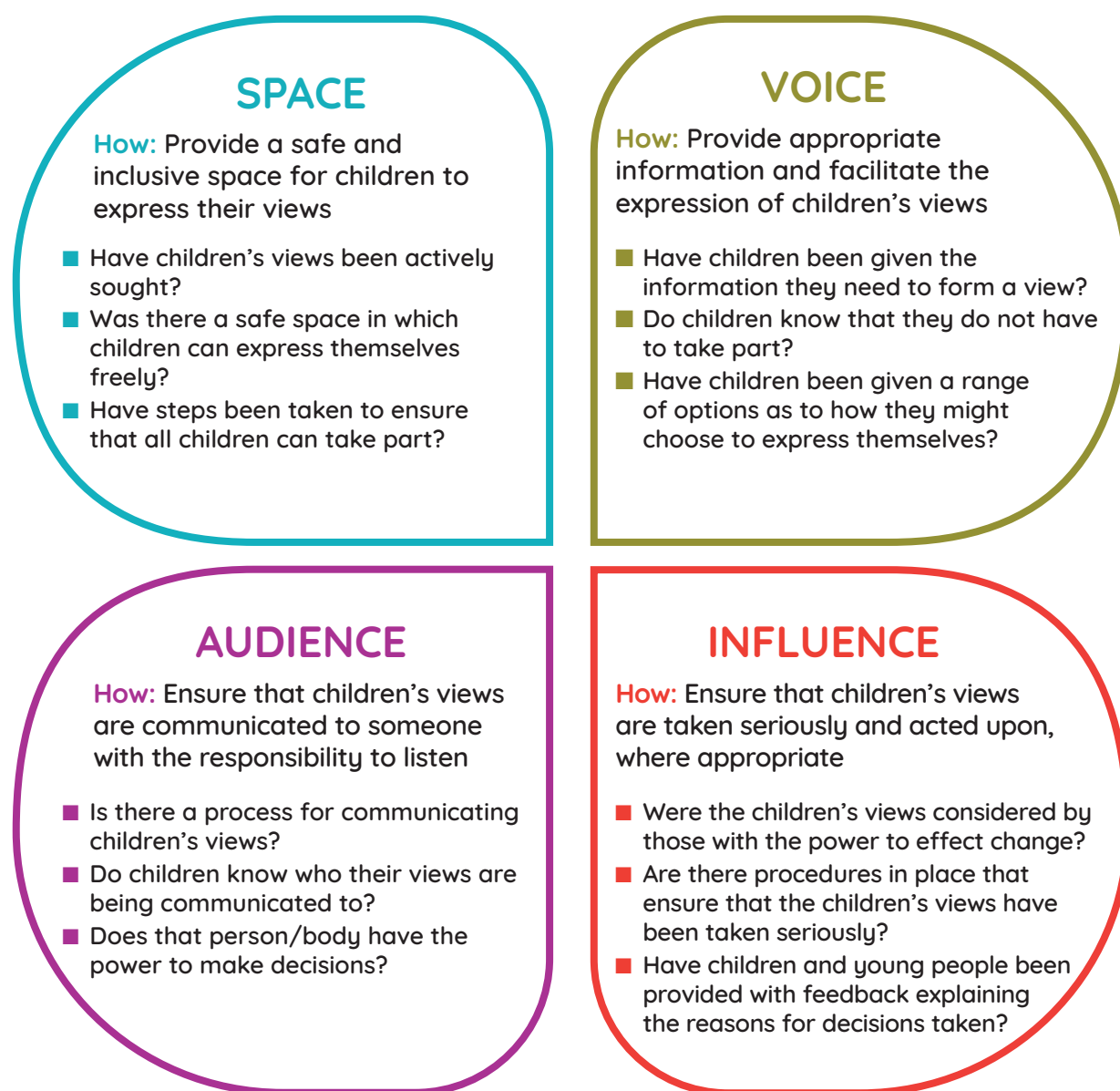
RUNG 3 – Tokenism: Adult-led activities, in which youth may be consulted with minimal opportunities for feedback.

RUNG 2 – Decoration: Adult-led activities, in which youth understand purpose, but have no input how they are planned.

RUNG 1 – Manipulation: Adult-led activities, in which youth do as directed without understanding of the purpose for the activities.

³. Youth Power (2020) Three models to consider when integrating youth participation in programs-accessed on 02.02.2022 <https://www.youthpower.org/youth-drg-toolkit-3-models-integrating-youth>

In 2007 Laura Lundy developed a model⁴ to support decision makers to understand and fulfil Article 12 that simplified the concepts to space, audience, voice and influence. This model has been used by a range of organisations who have adapted it including to provide checklists for organisations.



Within the HIV sector we have seen specific actions to develop and gain endorsement for approaches that meet the commitment to youth participation. The Global Consensus Statement on Meaningful Adolescent and Youth Engagement is a joint effort spearheaded by Family Planning 2020 (FP2020), the International Youth Alliance for Family Planning (IYAAP), and the Partnership for Maternal, New-born & Child Health (PMNCH) launched during the International Conference on Family Planning (ICFP) in November 2018.

4. Lundy Presentation: Involving Children in Decision-Making: the Lundy Model. Professor Laura Lundy Centre for Children's Rights- accessed 04/01/2021 https://ceforum.org/uploads/event/event_documents/594/LUNDYMODELCEX.pdf

The statement committed signatories to ensure engagement is rights based, transparent and informative, voluntary and free of coercion, respectful of young people's views, backgrounds and identities, and safe⁵.

Most recently an article from Oliveras and Cluver et al⁶ presented a framework called RIGHTS for work in the HIV sector with young people that is relevant across clinical trials, observational studies, implementation science, service delivery, and policy development. Reflecting much of the work that has gone before they call on organisations to ensure that work with young people is **Resourced, Impactful, Genuine, Harmless, Teen Friendly, and includes Skills Building**.

All these frameworks share common themes and as you use the guideline you will see that the work, we have done pulls many of these together but also provides more practical and specific actions for organisations to support them to meet existing commitments but also to ensure they are working with young people affected by HIV in a truly meaningful and ethical way.

WHAT DO 'MEANINGFUL' AND 'ETHICAL' PARTICIPATION LOOK LIKE IN PRACTICE?

In the Global Consensus meaningful adolescent and youth engagement is defined as:

Inclusive, intentional, mutually respectful partnership between adolescents, youth, and adults whereby power is shared, respective contributions are valued, and young people's ideas, perspectives, skills, and strengths are integrated into the design and delivery of programs, strategies, policies, funding mechanisms, and organizations that affect their lives and their communities, countries, and world.⁷

5. PMNCH (2018) Global consensus statement meaningful adolescent & youth engagement. Partnership of Maternal, Newborn and Child Health.

6. Oliveras and Cluver et al (2018) Nothing About Us Without RIGHTS—Meaningful Engagement of Children and Youth: From Research Prioritization to Clinical Trials, Implementation Science, and Policy. *Acquired Immune Deficiency Syndrome* Volume 78, Supplement 1, August 15, 2018

7. PMNCH (2018) Global consensus statement meaningful adolescent & youth engagement. Partnership of Maternal, Newborn and Child Health.

We asked the young people involved in the development of the *We Matter Value Us Guideline*, about what this meant to them in practice. They described *ethical engagement* in terms of belonging, acceptance and being respected. They described transparent and honest relationships, where they felt safe and where they would not be manipulated or exploited. For them *meaningful* meant being involved in decisions that matter and true collaboration where they had the opportunity to make a difference. They described partnerships that build their capacity and tap their true potential and where organisations were accountable to young people.

We asked them to reflect on their experiences and identify based on these definitions areas that still required improvement.

“

I valued just being respected. Since that project,

I have gone back to that team several times and they always help me.

It shows that it was a valuable experience because I could

keep drawing from that and it continues to be beneficial to this day.

”

Young person, UK

While there were many people who reported improved partnerships with organisations, programmes and policy there were still several young people who shared stories where they were not being treated in an ethical way with examples of being coerced into making testimonies and sharing their HIV status, situations where their pictures or words were used without permission and at times embellished or manipulated for greater effect. They also detailed partnerships that did not demonstrate respect for their contributions.

“

I saw on the programme that I was giving a testimony.

I was uncomfortable, that wasn't what had been discussed

but I just did it anyway.

”

Young person, Zimbabwe

Some young people shared examples of safeguarding failures when attending events where they felt unsafe or unsupported, and at times were put in situations that made them vulnerable such as travelling at night alone, staying in unsafe premises, or arriving unprepared for different contexts.

These stories are a reminder of areas where there is still room for improvement. We hope the guideline will provide guidance and recommendations for organisations and that working together we can ensure more meaningful and ethical engagement of young people living with HIV.

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