

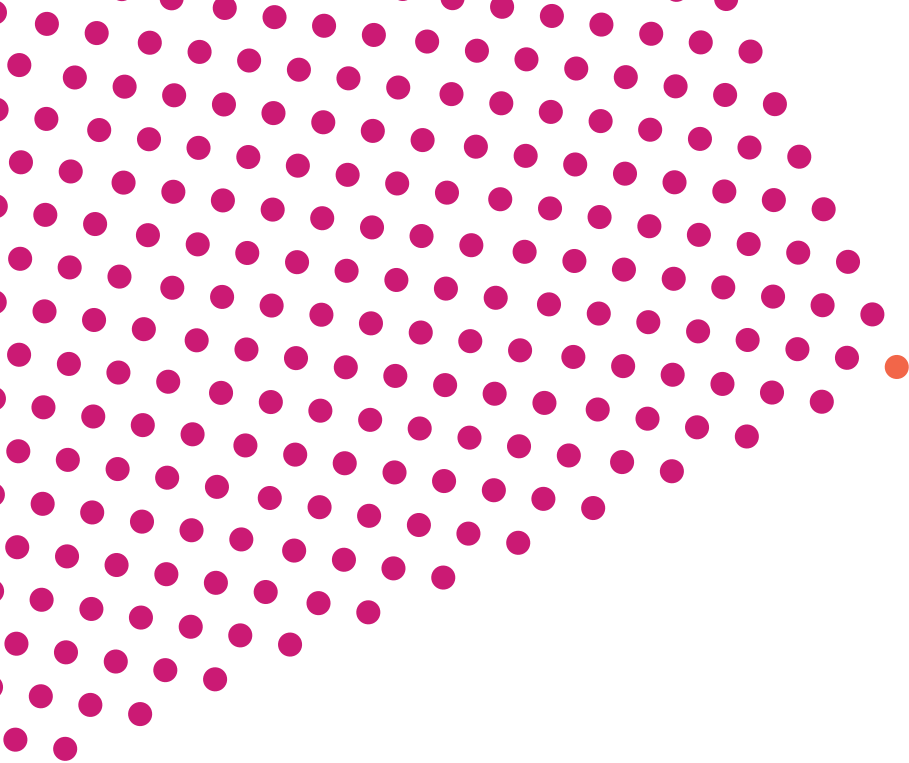
READY

to advocate

A guide for
young people living with HIV



GLOBAL NETWORK OF
YOUNG PEOPLE
LIVING WITH HIV



Acknowledgments

Thank you to Y+ network members from around the world for sharing their experiences as advocates for this guide. In particular we would like to acknowledge the special contribution of Chimumbwa Mubanga, Kelvin Makura, Phindile Nhleko, Audrey Nosenga, Bakita Khasada, Alexander Stanciu and Cédric Nininahazwe.

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READY+ aims to advance sexual and reproductive health and rights (SRHR), psychological wellbeing, care and treatment with, by and for 30,000 adolescents and young people living with HIV in Mozambique, Swaziland, Tanzania and Zimbabwe. The programme is being implemented by an innovative and multi-disciplinary consortium of youth, SRHR, HIV and communication partners. READY+ is one of a portfolio of projects being implemented under the READY programme. For more information, visit www.aidsalliance.org/readyplus



Introduction

This booklet is for young people living with HIV who want to be involved in advocacy. The booklet asks some important questions about why you want to be an advocate, and the issues that you care about. It offers suggestions for ways to get involved, top tips for your work, as well as some words of inspiration from famous people.

There are many guides that tell you how to **do** advocacy and how to plan a campaign or a set of activities which we will refer to in this guide, but this is about learning more about **you** as an advocate.

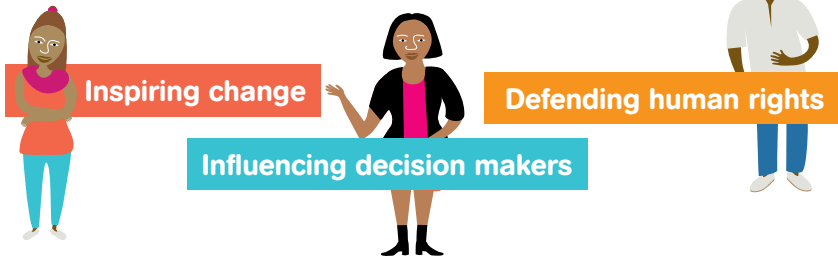
“A change is brought about because ordinary people do extraordinary things.”

BARACK OBAMA



What is advocacy?


Advocacy means different things to different people.



Here is one helpful definition provided by the International Planned Parenthood Federation (IPPF):¹

“Advocacy means identifying and calling for change. Advocacy calls for changes in laws, policies, practices and structures in order to improve people’s lives.”

Advocacy is not just about raising awareness of an issue, it is about trying to seek change in the policies, practices, systems, structures, decisions and attitudes that cause discrimination, exclusion or injustice.



“I am angry. We should all be angry. Anger has a long history of bringing about positive change. But I am also hopeful, because I believe deeply in the ability of human beings to remake themselves for the better.”

CHIMANDA NGOZI ADICHIE

1. IPPF (2011) Want to change the world? Here's how. Your action for change toolkit.



Advocacy can happen at different levels

It can be local work done in your community, advocating for access to and delivery of services or the allocation of resources, or it can be at national or international changing policies or priorities to attract attention and investment. All of these are linked, and therefore changes at one level can trigger change at a different level.

Mobilise others to action

Advocacy is often about the ability you have to mobilise others, increase attention to an issue and encourage people to care about the issue and to act to change a practice or a law.



© UN Women/Ryan Brown

Yana Panfilova, Y+ Steering Group member, speaks on a #WhatWomenWant panel with Ambassador Deborah Birx at the 2016 High Level Meeting on Ending AIDS, New York.

Advocacy can be loud or quiet

There are different ways to advocate and it is not necessarily about important speeches or global briefings. It may be a conversation or a presentation of critical evidence that changes minds.


Advocacy is about leaders and decision makers

The targets of your advocacy will be those that can make a difference, those that can change things, the decision makers at different levels – it could be heads of households, community leaders or even presidents of nations.



What is the role of an advocate

Advocacy happens at different levels and in different ways. As an advocate there are different roles you can play. On the next page is a helpful tool to illustrate some of those roles and the varied relationships you may have with the advocacy targets, those people whose minds you want to change and others affected by the issue.²



“When the whole
world is silent, even
one voice becomes
powerful.”

MALALA YOUSAFZAI

2. Tearfund (2014), Advocacy guide.
https://learn.tearfund.org/en/resources/publications/roots/advocacy_toolkit/

Role	Characteristic	
Represent	Speak on behalf of people	
Accompany	Speak with people	
Empower	Enable people to speak for themselves	
Mediate	Facilitate communication between people and decision-makers	
Model	Demonstrate a policy or practice to people or policy-makers	
Negotiate	Confer with a decision-maker to settle something	
Network	Bring people together to speak jointly	
Lobby	Persuade a decision-maker to do something	
Mobilise	Encourage people to take action to influence a decision-maker	
Bargain	Negotiate the settlement of something	



Advocate



Targets/decision-makers/those in power



Those affected by a situation

Am I an advocate?

Anyone who is affected by, or interested in, an issue or a problem can be an advocate. There are no special requirements. The most important thing is your passion for the issue and your desire to support positive change.

For young people living with HIV there can be an assumption that you must be involved in advocacy, that you have a duty to advocate. This is not the case! Living with HIV doesn't make you an advocate.

Being an advocate is about supporting change through being informed, thinking about who your targets are and finding the evidence that is needed to persuade people to change. This involves gathering information, planning your work and reviewing your progress.

Being a **young** advocate has benefits, your enthusiasm, energy and creativity can mobilise and inspire but there can also be challenges for young advocates around power, influence and levels of experience that can make things more difficult.

The most powerful advocates are those people who are **authentic** – who speak with knowledge and experience – and have **legitimacy** – who are part of the communities on behalf of whom they advocate or who have experience and knowledge around those issues. There are also people who can be **persuasive** and can deliver powerful messages.



This **authenticity**, **legitimacy** and **persuasiveness** come from caring about an issue and being passionate about the need for change. This is important when we think about our work as advocates. Does this matter to me? Is this what I really want to change?

At times people are asked to speak about issues that they are not passionate about and the impact is lessened.

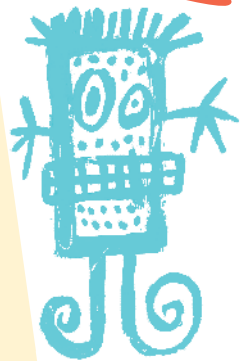
Use these questions to help you think about your role as an advocate and how to prioritise your messages. If the issue is not the one you care about find someone else, don't try and do everything yourself.



- What are my passions, what do I care about most?
- What makes me angry?
- What are my strengths?
- What strengths do people see in me?
- Which of these things do I like doing? Networking, speaking, writing, lobbying, organising, mobilising, representing?
- What makes me good at it? Energy, persistence, creativity, legitimacy, presence, passion, knowledge, experience?
- What emotions does advocacy stimulate? Anger, frustration, excitement, optimism?

“People were feeling pity for me and that made me more nervous and uncomfortable.”


YOUTH ADVOCATE



Giving my testimony

Many people living with HIV share their 'story' or 'testimony' with others to challenge stigma, to educate or inform people and to inspire and mobilise for change. For young people their first experience of advocacy is often when they are asked to share their stories. But not everyone is comfortable sharing their story, or it is not appropriate. Young people shouldn't be asked to do this unless they want to, and they are supported to think about potential consequences. Perhaps they haven't shared their status with others before or perhaps they have not had the opportunity to think through the implications of sharing?

Sadly, too many young people are pressured into disclosing their status and often this is their first experience as an advocate. It can lead to stigma, discrimination and unwanted visibility. If you are asked to give a testimony be clear about why you are being asked to do it and what it can help achieve. Think through some of these questions to help.


- 
- Do I want to share?
 - Do I want to share with these people?
 - Will my story be used in other spaces, in the media, on the internet?
 - What do I want to share? Perhaps only some of your history or parts of your life living with HIV.
 - Think through the questions you may be asked and whether you are comfortable answering them.



These are the kinds of intrusive questions young people have been asked. Think about your answers, prepare your story, think about whether you are happy to share.

Decisions about sharing your HIV status are a personal matter. You have the right to choose if, when, to whom and how, to disclose your HIV status. You should never be pressured to disclose your status in order to be involved, nor should an organisation share your status without your permission.

Take time to figure out whether you want your HIV-status or identity to be commonly known in your community, what are the negative and positive consequences, and what support will be available to you?



“If you ever think you’re too small to be effective, you’ve never been in bed with a mosquito!”

WENDY LESKO

Doing advocacy

So, you have thought through the things you are good at and the strengths you bring to advocacy and thought about how you want to use your experience of living with HIV in your advocacy.

What can I gain by being an advocate?

Being an advocate can be an exciting and powerful experience for young people, providing opportunities to be part of movements and actions to bring change. What kind of benefits would you hope for? Here are some ideas, can you think of others?

- A chance to meet different people who share the same passions and experiences
- Gain knowledge about important issues
- Feel motivated and motivate others
- Find mentors to support your learning and offer advice
- Learn about your community, find out about the issues that matter most
- Gain global awareness, learning from other young people living with HIV in other countries
- Build your confidence and self esteem
- Make a difference to your community and the wider world
- Gain skills and experience in communicating, researching, documenting
- Develop a career pathway

Things to remember when you work as an advocate

Don't be the 'token' young person

The attention on young people within the HIV and wider health sector has led to much greater engagement of young people and more meaningful participation. However, there are still many organisations, conferences, meetings that are aware they should be 'seen' to be working with young people and yet don't. In these cases, they request the presence of a young person on their panel, in their video, in their team but they are not committed to working with young people as equals. If you are asked to be part of something as a youth advocate, ask the organisation about how they engage young people and ask about other young people who are representing. Make sure this is a genuine space where your voice will be heard.

"Some young people are used as puppets and people who speak the truth can be left out."

YOUTH ADVOCATE

"I have to be strong, I will always say what I want."

YOUTH ADVOCATE

Power and pressure from older people

Young people are often asked to be part of events, meetings or discussions to represent young people and are outnumbered. This can lead people to feeling unsure or lacking in confidence to speak, they may not feel listened to or that older people are overruling them or undermining their ideas. It is important to remember that as a young person you have legitimacy to represent your peers, that you have been given that space because you are there to speak for your community and others who have shared similar experiences. You should not feel that adults can limit your ideas or your actions. When you work with an organisation, suggest that they engage more than one young person and ask them how they manage issues of power or imbalance and how they ensure young people can meaningfully participate.

Be a voice for others

When you have the space and the platform to speak on the issues that matter to you remember you are also there representing others, people who share your passion and interest, perhaps share your experiences. Gather information and opinions from these people to ensure you are informed and you have their voices to support you.

Know your boundaries

We all have limits, things we are not prepared to discuss, things we are uncomfortable doing. This may be to do with an issue you are not prepared to talk about – your HIV status, your personal life, politics, religion? Or it might be a clear boundary on the type of organisation you would work with – political organisations, religious organisations, drug companies. You might also have boundaries such as not being on a panel unless there is more than one young person, a panel that has equal gender and age representation or it might be to do with what you are paid or the support you are given. Think about your boundaries and stick to them.

Keep it simple

If you are good at what you do you are likely to be in demand. Someone who is passionate, interesting and a good communicator is likely to be asked to attend all the meetings and conferences. Remember to think back to the questions you asked yourself about the issues that really matter to you. Don't take any opportunity just for the chance to travel or speak. Remember to be authentic and speak about the issues you know and understand. There will be others who can take up other opportunities.

Know your opposition

As advocates you can be caught up in your own issues and arguments. It may seem clear to you that there is only one answer, but others may see things differently. Learn about the opposing views, learn about the arguments of others, so that you are prepared to challenge and be challenged, and your approach will be stronger.

Take care of yourself

Working as an advocate it can feel like the job is never done. Your passion for the issues, your commitment to challenging injustice can lead you to forgetting about yourself and your own needs. Make sure you take time to rest, eat well and find people to talk to, to share the highs and lows with you and provide you with support. Your work is so important you need to be at your best and sometimes that means taking a break.



Find your mentor

A mentor is a person who can provide guidance and help you learn. Mentors share their experiences, ask questions that help you think things through, and challenge you to grow by trying new or difficult things. Mentors can provide wonderful support and inspiration and they also get the amazing opportunity to work with and learn from you! There will come a time when you can become a mentor to younger advocates and share your experiences and advice.



“This world demands the qualities of youth: not a time of life but a state of mind, a temper of the will, a quality of imagination, a predominance of courage over timidity, of the appetite for adventure over the love of ease.”

ROBERT KENNEDY



How to do advocacy

There are lots of resources available to help you plan your advocacy work providing you with steps to follow to help you plan. References for these tools are included at the end of this booklet.

IPPF developed a simple set of seven steps that may be useful. Think through each of these.

1. What needs to change?
2. Who can make that change happen?
3. How can I influence my advocacy targets to make that change?
4. How can I ensure meaningful participation of young people?
5. Who can I work with?
6. What obstacles might I face? How can I overcome obstacles and risks?
7. How will I monitor and evaluate my advocacy to prove that it is working?

You can learn more about these steps in the resource *'Want to Change the World? Here's how ...'* It also includes planning checklists and strategies for different audiences. You can download it here:

www.ippf.org/resource/want-change-world-heres-how-young-people-advocates



Choosing my issue

Having passion and enthusiasm can make you a powerful advocate. Caring deeply about an issue or being fascinated about a topic helps you to learn more and gives you the motivation for your work. When choosing your issue to advocate on think about what you are interested in and what area you would like to develop expertise in.

- Being focused or more specialised will give you an advantage. People will want to know your thoughts and hear what you have to say. Don't try to be an expert in everything.
- Talk to other people to know what the hot topics are, speak to your peers and work hard to be ahead of others on the issues that will matter. For example, as an advocate for young people stay up to date with the latest research on HIV technologies and consider how it will affect young people living with HIV.
- Learn about your context and how global issues may play out in your community. Perhaps this is a new approach or a new policy. What will it mean in your context? Can you help people understand the application by using your own experience?
- Keep it current – stay up to date, don't let your messages become stale. If people hear you saying the same thing over and over they will stop listening.
- Know the global policies that can support you, know about the rights of young people and the rights of people living with HIV.

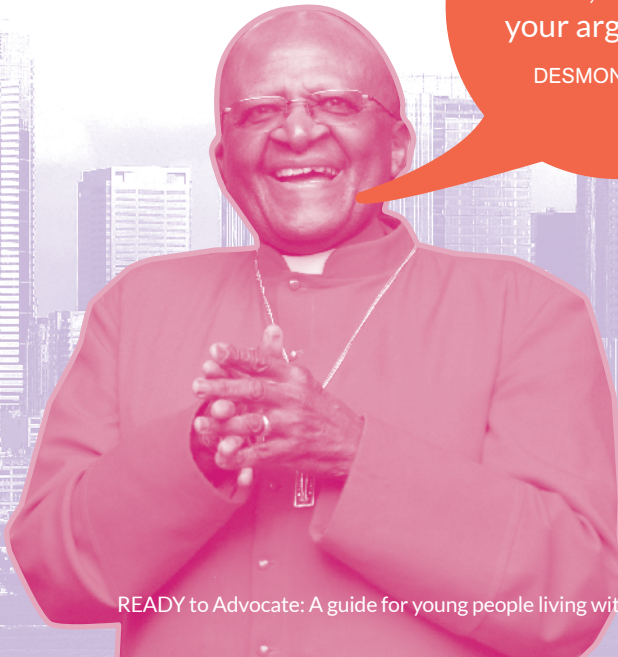
Building my messages

It is important that your messages are based on strong evidence and are current and accurate. Being able to bring issues alive through stories and real-life examples is also very helpful. As an advocate remember you are representing others. Make sure others are happy with your messages and that they reflect their reality. Test your messages on people and make sure they are clear and actionable.



"Don't raise your voice, improve your argument."

DESMOND TUTU



Who to work with?

Make sure you are being involved in advocacy for the right reasons and aren't being used. The recent attention on youth within the HIV response has meant a growing demand for young people to represent organisations, to participate in meetings and programmes.

Make sure you are working with people you respect and who share similar views. You may receive numerous offers but think about who you want to work with.

To assess whether this is the right organisation, learn about the work they do, ask others about them.

- Are they respected?
- Are they affecting change?
- Are they working well with young people?
- What do other youth advocates say about them?
- Will working with them help me learn, grow my skills and help my organisation?
- Do my peers and colleagues see the value of what I am doing?
- Do you get asked about the issues and decisions to which you feel you can make the best contribution?

“Don't let complexity stop you. Be activists. Take on the big inequities. It will be one of the great experiences of your lives.”

BILL GATES

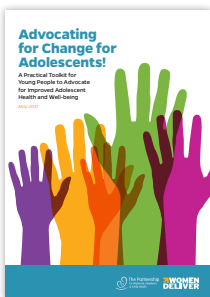


Understanding the organisation and learning about the people who work there is important.

- What is their stance, ethics, approach?
- Do you want to be associated with their message for the long term?
- Do you like their strategy?
- Have they explained things clearly to you?
- Ask them questions about your role. What will you do, what support will they give you, how will they follow up?
- What are they doing for young people?

There are resources you can read that offer ideas on how to gather your evidence, how to plan a situation analysis, what to look for in partnerships and tools for gathering evidence.

This booklet has been developed by drawing on the experiences of young people in the Y+ network working as advocates. The World Health Organization (WHO) also drew up some helpful points from the experiences of young people on how to do advocacy with government to encourage them to engage with young people (see page 22). You can download *Advocating for Change for Adolescents! A Practical Toolkit for Young People to Advocate for Improved Adolescent Health and Well-being* here: www.who.int/pmnch/knowledge/publications/advocacy_toolkit.pdf



"Every moment is an organising opportunity, every person a potential activist, every minute a chance to change the world." DOLORES HUERTA



From WHO (2017), *Advocating for Change for Adolescents!*

- Specify the event that you want to attend and explain why. Make sure you follow developments leading up to the event closely so that you know what you are talking about.
- Establish your credibility time and time again. Become an expert in your area and show officials that you know your stuff.
- If you meet one of your government’s delegates at any event, introduce yourself, exchange contact details and follow up the contact to establish a strong relationship with them.
- Make accurate statements, backed up with evidence, in order to demonstrate that you are an expert in your field.
- Liaise with and report back to other non-governmental organisations (NGOs) working in your field and for the government on specific issues; this will enhance your credibility.
- Consult other young people you work with and ensure that you have authority to speak on their behalf. Speaking on behalf of a broad constituency makes your advocacy more persuasive.
- Collaborate with other civil society organisations in order to speak on behalf of a broader constituency. Think about partnerships with organizations outside of your immediate sector whose mandates overlap or align with your own.
- Know your national priorities and how to align them with your “asks”.
- Employ “provocative diplomacy” – applaud your government for what it is doing right and focus on solutions to the remaining challenges.
- Be courteous and polite to everyone you meet.
- Make it known if, for example, you have a contact in your country’s mission in New York.
- Follow-up, follow-up, follow-up by every means possible!
- Be prepared to respond. You may be asked to contribute at a moment’s notice.
- Be prepared to do more than is expected of you!

Being a role model

As a young advocate, you may be provided with platforms to speak, or space in the media to represent your community. How you do this and how you are seen are important. You have the opportunity to be a role model for other young people living with HIV in the way you work with others and how you approach your advocacy work.


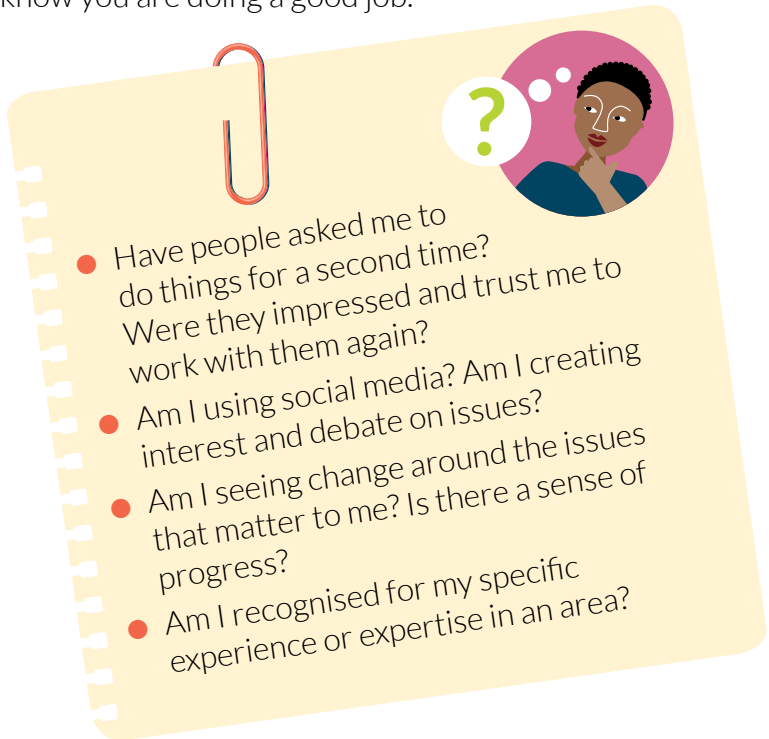


Remember how important it is to be authentic in what you do. Show other young people how you work with honesty and transparency and how you make considered choices about the work you do and with whom. Some young advocates are drawn by the opportunity, the financial reward, the attention, the foreign travel. Think about why you want to do this work and think about how you may be seen by others.

Be a mentor to others. Too often the same young people are asked to speak or take part in events. Organisations tend to select people they know and trust. Help others reach the same spaces as you, recommend, refer, mentor and support so there are more opportunities for others and we have sustained advocacy by supporting the next generation. There will come a time when you are no longer a 'young person' and it is important you are able to step aside and allow space for the next generation of advocates. You can continue to support the work you are passionate about through working as a mentor.

Measuring your impact

The resources on page 26 offer useful ideas on how to measure the success of your advocacy work. There are tools and ways of capturing the impact you have achieved. You may also think about ways you know you are doing a good job.


A green pencil with a brown eraser and a sharp lead tip, pointing towards the text on the right.

Keep logs of your activities and your contacts, keep a diary of the conversations you have to help track your progress.

Final thoughts

Being an advocate is a powerful role where you can make a real difference. Your experience and knowledge of the issues can change hearts and minds. You also have the opportunity to be a voice for others not able to take up the spaces, or a voice for people who are ignored or don't feel confident to speak. You have a responsibility in this role and that is why thinking carefully about who you are as an advocate and what issues you can have the greatest impact on, are so important. It is also important for you to be critical about whether you are best person for each opportunity – do you have the legitimacy or is there someone better placed to do the work? Have you done the research to understand the issues? Do you have the evidence? Do you have the current knowledge? Have you asked others to share their thoughts and opinions?

The creativity, energy and enthusiasm that young people bring to the HIV sector and to advocacy within it can generate immense change. Be part of the change!



“Don't give up trying to do what you really want to do. Where there is love and inspiration I don't think you can go wrong.”

ELLA FITZGERALD

References

GNP+ (2012) GIYP A Roadmap: supporting young people living with HIV to be meaningfully involved in the HIV response

Each chapter in this roadmap outlines one of the five steps towards GIYP A (greater involvement of young people living with HIV): 1. Understanding what is meant by the 'HIV response'; 2. Finding good reasons to become involved; 3. Linking you and organisations together; 4. Sustaining and growing your involvement; 5. Seeing Positive Health, Dignity and Prevention in action.

www.gnpplus.net/resources/giypa-roadmap/

IPPF (2011) What to change the world? Here's how ... Young people as advocates, your action for change toolkit

This toolkit is for young activists, volunteers, students and agents of change! It offers a step-by-step guide to help plan, implement or improve advocacy initiatives on young people's sexual and reproductive health and rights.

www.ippf.org/resource/want-change-world-heres-how-young-people-advocates

WHO (2017) Advocating for change for adolescents! A practical toolkit for young people to advocate for improved adolescent health and well-being

This toolkit was developed by young people, for young people, to be used by networks of youth-led and youth-serving organizations to change the world, through a joint initiative of the Partnership for Maternal, Newborn & Child Health and Women Deliver. The purpose of this toolkit is to guide the design, implementation and monitoring of an effective national advocacy action roadmap to bring about positive policy-specific changes to improve the health and well-being of adolescents.

www.who.int/pmnch/knowledge/publications/advocacy_toolkit.pdf

ATHENA/ GYCA (2015) Vision and voices

The Vision and Voices briefs were generated by the Global Youth Coalition on HIV/AIDS (GYCA) and the ATHENA Network as part of the Link Up Programme. They are drawn from consultations community dialogues and focus groups with young people living with and affected by HIV in Ethiopia, Uganda, Burundi, Bangladesh and Myanmar.

www.aidsalliance.org/resources/481-voices-visions-and-priorities

“Never be discouraged from being an activist because people tell you that you'll not succeed. You have already succeeded if you're out there representing truth or justice or compassion or fairness or love.”

DORIS HADDOCK



READY

to advocate

A guide for
young people living with HIV

Y+ is a network for and by young people living with HIV.

We're on a mission to make sure young people living with HIV can contribute to the HIV response.

We're ready to make and influence decisions that positively affect our lives. Are you? You can join us through Y+ Voices at www.yplusnetwork.org/blog/ and follows us on:



www.facebook.com/YplusNetwork/



https://twitter.com/Yplus_network



www.instagram.com/yplusnetwork/



“Far and away the best prize that life offers is the chance to work hard at work worth doing.”

THEODORE ROOSEVELT

www.yplusnetwork.org