

PAEDIATRIC BREAKTHROUGH PARTNERSHIP



BREAKTHROUGH CHAMPION ADVOCACY TOOLKIT



Elizabeth Glaser
Pediatric AIDS Foundation
Fighting for an AIDS-free generation



THE BREAKTHROUGH PARTNERSHIP AND YOU

About the Breakthrough Champion Advocacy Toolkit

This Breakthrough Champion Advocacy Toolkit is targeted towards strengthening the capacity of adolescents and youth to advocate for addressing HIV treatment inequalities to end AIDS. The Toolkit serves as a training manual for the Breakthrough Partnership's adolescent champions to develop advocacy skills and gain knowledge about HIV treatment gaps and differentiated service delivery — which is the offering of treatment service as per the needs of different groups of clients instead of one-size-fits-all approach.

The Toolkit provides information about foundations of advocacy, examples of how to plan for effective advocacy, and the resources to become an advocacy champion. It provides key messages on the advocacy goals of the Breakthrough Partnership. The Toolkit should serve as a reference for the ViiV Breakthrough Champions both in their engagement with this project to advance the service delivery framework, and in future HIV advocacy as well. The Breakthrough Partnership shows that when organisations work in partnership with one another, together with local stakeholders (government, clinics, communities, and AYPLHIV*) they can offer better services and improve treatment and care for children, adolescents, and young people living with HIV.

By working through the Toolkit, you should be able to do the following: define advocacy, identify your role as an advocate, discover how power impacts advocacy, share key messages about ending paediatric and adolescent HIV and AIDS, and describe ways that you can share your message as an advocate.

Acknowledgements

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We would like to give special thanks to youth advocates in Uganda - Ariel Peers, Asiimwe Rosette, Agaba Frank, Birungi Catherine, and Mukama Emmanuel for giving feedback that helped guide the development of this toolkit.

*AYPL HIV is the acronym used to denote "adolescents and young people living with HIV"

How to Use this Toolkit

This Toolkit is separated into different sections that are capitalized in red text and are as follows:



The scenarios found throughout the Toolkit are hypothetical and not intended to represent any particular person. Important vocabulary words to know are found in yellow boxes and **bolded** throughout the Toolkit. There is a lined section at the end of every page for personal notetaking. Helpful materials include this Toolkit, a pen or pencil, and a highlighter. Throughout the Toolkit, you will find icons that act as symbols to let you know what to do or what to expect.



Definition of an important vocabulary word



Think and Ink: You will reflect and write



Take Note: Additional key information

About the Paediatric Breakthrough Partnership

The ViiV Paediatric Breakthrough Partnership is committed to ending paediatric AIDS by increasing access to testing, treatment and retention in care for children and adolescents living with HIV. The partnership includes Aidsfonds, Elizabeth Glaser Pediatric AIDS Foundation (EGPAF), United Nations International Children's Fund (UNICEF), Paediatric – Adolescent Treatment Africa (PATA), ViiV healthcare and is convened by ViiV Healthcare's Positive Action.

Currently working in Mozambique, Nigeria and Uganda, the Partnership is introducing and scaling up interventions which are sustainable, evidence-based and replicable. Our activities are informed by the [Paediatric Service Delivery Framework](#), which enables us to maximize our impact by identifying and supporting activities based on local context and need.

We strongly believe in the power of partnership. Together, we work to amplify key advocacy messages at a global, national and local level, leveraging our individual networks for greater combined impact. We draw on partners' respective capabilities and strengths, sharing best practice, experience and lessons learned both between partners and externally to harness the added value of collaboration and demonstrate the power of a collaborative approach.

About The Paediatric Service Delivery Framework (SDF)

To meet its goals, the Breakthrough Partnership is using the Paediatric Service Delivery Framework (SDF) to identify gaps in care for infants, children and adolescents and propose practical solutions to address the gaps. As Breakthrough Champions, we would like you to have an overview of the framework. The SDF is a helpful tool for advocates because of the structure and guide it provides when tackling an important issue. To achieve your goals, the SDF can help to frame your plan of action in a way that is productive and realistic to the issue.

About the SDF

- The SDF is a programming tool used to advance collective thinking on global paediatric and adolescent HIV service delivery.
- It is designed to help individuals identify gaps in HIV testing, treatment, and retention for infants, children, and adolescents.
- It helps individuals propose solutions to the identified gaps and ensure ongoing and effective care is provided.
- The SDF helps programme managers define and implement priority interventions specific to their national and sub-national contexts.



Photo: Elizabeth Glaser Pediatric AIDS Foundation, Ricardo Franco, 2022

The SDF is for individuals who work at or with the following:



Government
ministries



Faith-based
and private
sectors



Non-
governmental
organizations
(NGOs)



Community-
based
groups



Networks and
support groups
run by, and directly
supporting people
with and affected by,
HIV



How to Use the Service Delivery Framework (SDF)

How does the SDF work?

It guides conversations around what is needed to address gaps and track progress to continuously improve paediatric and adolescent HIV programme quality.

How can you advocate for the SDF?

A good understanding of how the SDF is used will help identify the issues, who to engage, and what can be done. The SDF helps you plan advocacy activities and learn the skills needed to advocate. Let's find out how in the next section!



Photo: Elizabeth Glaser Pediatric AIDS Foundation, Amanda Ntambiko, 2019

The 3 Steps of the Service Delivery Framework

1. **Assessment** clarifies what the state of the epidemic is and where gaps lie in the continuum of care
2. **Solutions Matrix** defines which evidence-based interventions might be best suited for the context (should do's and could do's)
3. **Data Monitoring and Progress** informs assessment in a cycle of continuous quality improvement



FOUNDATIONS OF ADVOCACY

This section introduces basic concepts of advocacy, what it entails and what to keep in mind as you do advocacy.

Defining Advocacy



Advocacy

For the purposes of this toolkit, **advocacy** is defined as the ongoing process of changing attitudes, actions, policies, and laws by influencing individuals, groups, and organizations to achieve a goal.



Photo: Elizabeth Glaser Pediatric AIDS Foundation, Ricardo Franco, 2022

Let's break this down!



Advocacy is about influencing policies, laws, and practices that have a negative impact on the public.

- It aims to change how decisions are made, which can often take a long time.

Advocacy requires a call to action, not just raising awareness. A good question to ask is...

- "What do we want people to do?"



Think and Ink: Advocacy Experiences

What experiences do you already have with advocacy? Write down what you've done in the note section at the bottom of this page!



Power and Advocacy

People who have **power** to influence decision makers come from different areas of society.

1. Advocates should work to identify individuals who have **power** within institutions.
2. After identifying these influential people, the next step is to classify them as **allies**, **opponents**, or **undecided** people.



Power

Power is influencing or controlling people, resources, and events in some way.



Allies

- Agree with the plan
- May be willing to support with concrete actions



Opponents

- Against the plan
- Can do a lot of harm
- Can be worked *with* or worked *around*



Undecided People

- Have not taken a position
- Might be persuaded

Take Note!

These classifications can change. People who are allies today can become opponents tomorrow, and vice versa.



Think and Ink: People in Power

Who are the people in power in your life? Start with your family, then think more broadly. List them in the note section at the bottom of this page!



The Roles of an Advocate

What role you take as an advocate depends on several factors. Let's examine a scenario to identify these factors.

Scenario

Agatha, 16-years-old, is living with HIV and is a youth advocate for people living with HIV. She meets Prisca, a 15-year-old pregnant girl, who recently tested HIV positive. The midwife at the nearby health center recommends she attend antenatal care (ANC) at another health center, as she is a high-risk mother, but Prisca has no way to get there. How would you as a youth champion/advocate advise Agatha to support Prisca?



Context

Context is defined as the interrelated conditions in which something exists or occurs.

Advocate



Context



Affected People



Your Role

- Agatha and You! (A Breakthrough Adolescent Champion)

- Social and Cultural: What do the communities or families think about teen pregnancy?
- Legal: Are there laws around what age an adolescent can access health services?
- What social services are available in your area to help adolescents and pregnant women access health care?

- Prisca
- HIV positive adolescents
- Pregnant adolescents

- Ask Prisca's family to support her with bus fare
- Encourage Prisca to join a youth support group.
- Accompany Prisca to the health facility on occasion.
- Help her access social services in your community.
- Discuss options for Prisca to continue with her education.





No matter which advocacy approach you take, there are certain principles of good practice! These **important principles** include...

Accountability

Acknowledging and assuming responsibility for advocacy messages, decisions, and actions

Legitimacy

Ensuring that the advocate is the most credible to speak on the issue

Participation

Involving all the people interested in, and/or affected by, the issue

Representation

Making sure that when advocacy is done for other people, their views are accurately and fairly considered through all the steps of advocacy

“Youth advocates are able to speak up on behalf of the peers and be mediators in situations that the person on whose behalf they are speaking would not be able to speak for themselves.”

- Asiimwe Rosette



Take Note!

These values contribute to your success as an advocate, and help you avoid doing advocacy *on behalf* of others. It is important to *work in collaboration* with affected people!



Factors to Consider

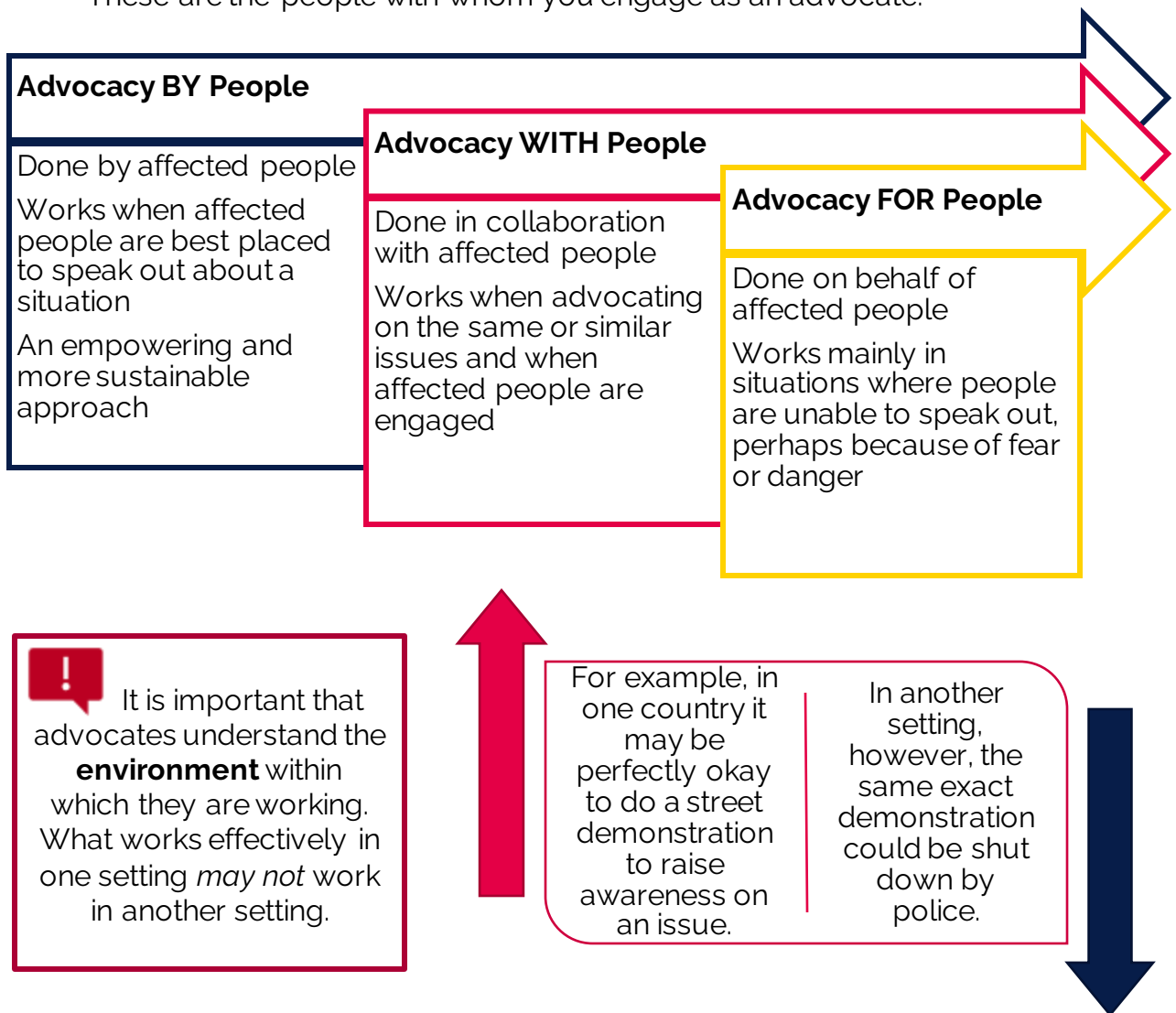
The core of advocacy is to influence factors that are not within one's control. The advocacy approach you take will vary based on several factors.

Geographic Location

- Where is advocacy being done?
 - In a village, district, county, country, region, or globally?

Affected People

- Is advocacy being done **by**, **with**, or **for** the affected people?
 - These are the people with whom you engage as an advocate.



Keep in mind, advocacy aims to **build consensus** for an idea, **not impose** it on others.

PREPARING FOR ADVOCACY

How to Plan for Advocacy

When preparing for advocacy, you must first identify the problem, come up with a solution, and then decide how to achieve your proposed outcome. This requires an organised process. Below are the questions you should ask yourself before advocating.

5 Key Advocacy Questions

- What is the problem?
- What is the desired solution?
- Who is the advocacy target(s)?
- What advocacy activities can I do to bring about the solution?
- What additional context should I keep in mind while planning my advocacy?

On the next two pages, you will find scenarios putting these 5 key advocacy questions into practice. A blank table is also provided so you can easily apply these questions to situations you come across!



Scenario A

Jane is a 10-year-old living with HIV. She lives with her 15-year-old brother, Tom, who became the head of their household following their parents' deaths and her two younger brothers. They struggle to survive as a family. You learn about Jane's predicament as an advocate for young people living with HIV in your community. What would be your response?

What is the problem?	Jane and her siblings are orphans and vulnerable children, who need support.
What is the desired solution?	Helping Jane and her family find a way to have their basic needs met.
Who is the advocacy target(s)?	Extended family members; School leaders; Religious leaders; Neighbors; Community leaders; Health workers
What advocacy activities can I do?	<ul style="list-style-type: none"> • Discuss with Tom and Jane their needs and help them determine the best solution • Understand what social supports are available in the area and how to access them • Help Jane and Tom reach out to a teacher, counsellor, or health care worker they feel comfortable with • Support Jane as she works to access social services for her and her family
What additional context should I keep in mind?	<ul style="list-style-type: none"> • Cultural and societal context in your country: how is this issue being perceived at the community level, at school, by church members, etc.? • Government programmes and policies around children and youth • The existence (or lack) of programmes to support orphans and vulnerable children



Scenario B

Peter is a 15-year-old adolescent living with HIV who lives with his elderly grandmother. He has been doing well until last holiday when the counsellor noticed he had started to keep to himself while at the clinic and that his viral load was no longer suppressed. His treatment buddy told the counsellor that he had stopped taking his medicines a while ago due to exposure of his HIV status at school by the class teacher. How would you support Peter as an advocate for young people living with HIV in your school/ community?

What is the problem?	Peter has stopped taking his medicines after his HIV status was revealed by his teacher. As a result, he is no longer virally suppressed and has been isolating himself.
What is the desired solution?	Provide Peter with the support needed to improve his physical and psychosocial well-being by reducing the stigma that Peter and other adolescents living with HIV face at school.
Who is the advocacy target(s)?	Teachers and other school staff; Students and peers
What advocacy activities can I do?	<ul style="list-style-type: none"> • Work with Peter's health care worker, treatment buddy and grandmother to encourage him to continue with his treatment and participate in peer activities at the health center • Educate the school community about HIV to reduce stigma and support students living with HIV • Encourage the school administration to create new policies to make sure other students do not have their status revealed at school • Partner with school staff and other students to create a peer support programme to champion adolescent health
What additional context should I keep in mind?	<ul style="list-style-type: none"> • The support that Peter needs to continue with his treatment in a safe manner • The specific context of your school and how the school administration has worked with students in the past • Education policy in your country about what can and cannot be discussed in schools • Existing student clubs that might want to help create a peer support programme



Think & Ink: Your Turn to Plan for Advocacy!

Brainstorm a situation that you think needs an advocacy intervention. Use the questions below to think about how to address the issue that you need to work through.

What is the problem?	
What is the desired solution?	
Who is the advocacy target(s)?	
What advocacy activities can I do?	
What additional context should I keep in mind?	



BECOMING AN ADVOCACY CHAMPION

Now you have a plan and are ready to advocate! This section explains how to implement an advocacy plan and provides messages you can use to advocate for the goals of the Breakthrough Partnership.

Your Advocacy Message

An advocacy **message** is a concise and persuasive statement about the objective. The message should include:

- What you want to achieve
- When you want to achieve it
- How you propose to achieve it
- What action you want the audience to take



Message

A **message** is defined as a communication in writing, in speech, or by signals; an underlying theme or idea.

You will need to consider these four items when crafting your message:

Language

- What words will you choose to get your message across?



Source/Messenger

- Who will be able to connect with the target audience?



Format

- Which way(s) will you deliver your message for maximum impact?



Time and Place

- When and where are best to deliver the message?

Take Note!

Having a **message** helps you...

- be clear about what you want and why
- stay on track and be consistent to get attention from decision makers
- provide a persuasive argument!







Your Advocacy Message

Here are some key messages that you should communicate as a champion who will engage in many different situations. *Please note: The data provided in the key messages are from the year 2020, unless otherwise noted.*

Key Message 1

- The Paediatric Service Delivery Framework helps programme managers identify gaps in HIV services based on data from health facilities to track progress and challenges. The tool provides steps to address gaps based on national and sub-national contexts, as well as the unique needs of the patients. It presents different actions that can be taken to locate, test, treat and retain children and adolescents in HIV care.

Key Message 2

- Interventions to locate HIV positive mothers, children and adolescents, link them to care and retain them are key to preventing future transmission of HIV. Despite 85% of HIV positive pregnant women having access to antiretroviral treatment, more than 160,000 new infections occurred through mother to child transmission. Meanwhile adolescents and young people represent a growing share of people living with HIV. 400,000 young people between the ages of 10 to 24 were newly infected with HIV. Health care workers should use a mix of targeted methods, such as index family-based testing, testing in schools and of sick children in hospitals to close testing gaps. To be successful, improved and scaled-up diagnostics are needed.

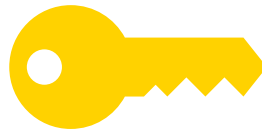


Key Message 3

- HIV-positive infants, children and adolescents should be linked to accessible and high quality treatment services. Only 54% of children under the age of 15 living with HIV have access to the medication they need compared to 73% of all people living with HIV. Optimal antiretroviral treatments should be made available as quickly as possible. Ensuring that HIV services are decentralized and provide additional services such as integrated mental health counselling, disclosure support and peer support is also important.

Key Message 4

- Families and communities should closely collaborate with health care workers to ensure that children and adolescents are retained in care with treatment support to achieve viral suppression. Only 40% of children living with HIV have suppressed viral loads. Children's and adolescents' care and adherence can be supported through viral load testing, peer support, and regular appointment follow ups.



Country Data – Mozambique, Nigeria, and Uganda

As you have learned so far, it is important to have data to support your advocacy. The table below provides you with important data for this project about new infections, people living with HIV, treatment and prevention of mother- to-child transmission of HIV in Mozambique, Nigeria, and Uganda.

Please note: The data provided are from the year 2020, unless otherwise noted. All data are from UNAIDS and UNICEF.

	Mozambique	Nigeria	Uganda
New HIV infections for children, ages 0-19	30,000	29,000	11,000
Young people living with HIV, ages 0-19	210,000	190,000	160,000
Percentage of children, ages 0-14, on treatment	64%	45%	63%
Percentage of young people, ages 10-19, on treatment	47.5%	52%	70.6%
Mother to child transmissions averted	20,000	7,600	19,000
Pregnant women with HIV receiving ART	98%	44%	98%
Mother to child transmission rate	13.49%	24.94%	5.85%



Sharing Your Message

In this section, you will learn how to share your message in a variety of ways. A clear message ensures the targeted audience understands your message and can easily share it with others.



Photo: Elizabeth Glaser Pediatric AIDS Foundation, Ricardo Franco, 2022

An advocate needs to be able to provide key information in an accessible and engaging way. Some formats that can be used for sharing a message are posters, flyers, pamphlets and digitally.



Another great way to amplify your advocacy message and to reach a wider audience is to engage with the **media**. The **media** refers to a diverse array of written, broadcast, or spoken communication.



Think and Ink: The Media

Some common forms of media include television, radio, and newspapers. What forms of media are most popular where you live? Write down your ideas in the note section at the bottom of this page!

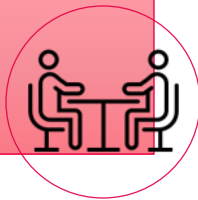


Meetings in Advocacy

Meeting with a decision maker is one strategy that is used by an advocate to deliver a message. **Face-to-face meetings** are closely associated with **awareness raising** but they are different. Before delivering a message in a meeting, think about any written materials you may want to share. Ask the person you are meeting with if they have any questions.

- Speaking directly to the target of advocacy efforts
- Explaining in detail the problem and proposed solution
- One of the most effective tactics to influence decision makers

Face-to-Face Meetings



- Informing people about the issue
- Building confidence of decision makers around the issue
- Usually, the first step in advocacy and is often used when the information is hidden or complex

Awareness Raising



Photo: Elizabeth Glaser Pediatric AIDS Foundation, Amanda Ntambiko, 2019



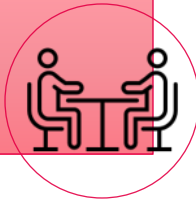
Scenario

Grace, 24-years-old, is passionate about sexual and reproductive health and making sure that all youth and adolescents can access resources and prevention methods — such as condoms and other forms of contraception — to prevent pregnancy, HIV, and other sexually transmitted infections. However, many of the policies in her country make it difficult for teenagers and young people to access sexual and reproductive health services. Grace would like to change those policies but doesn't know where to begin.

*How could Grace use both **face to face meetings** and **awareness raising** to advocate for this issue?*

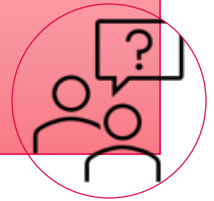
- Grace could talk to leaders at the health facility or within her community to explain why she cares about sexual and reproductive health, and why it is important to her peers.
- She could provide them with her recommendations about how to improve sexual and reproductive health service access for adolescents.

Face-to-Face Meetings



- Grace could talk to her peers about the importance of preventing pregnancy, HIV, and other sexually transmitted infections.
- She also could create resources, like fact sheets or a social media campaign, to help educate adolescents who are less familiar with these topics.

Awareness Raising



“Once we raise awareness, young people approach us to ask tell us more about our life stories. How did we get here? How do we have such courage to speak? They want to learn even more about us because they can see that we are healthy, we are having fun and living our lives.”

– Agaba Frank, Ugandan Youth Peer



Electronic Advocacy

Electronic advocacy (e-advocacy or online advocacy) means using Information and Communication Technologies (ICT) as part of an advocacy campaign. It has a huge reach and enormous potential for spreading awareness and bringing about change!

The most common forms of e-advocacy include:

- **Email** – allows you to send the same communication to a large number of people
- **Social Media** – lets you to communicate with others who share similar interests, and therefore identify and engage potential new supporters
- **Websites** – provides much needed visibility and legitimacy, and are a good tool for gathering email addresses and linking to social media platforms

Take Note!

Use the following tips to post and engage on social media:









- Keep content short
- Use pictures and videos
- Engage with other accounts
- Use hashtags
- Retweet, share, and like others' posts



Please reference your UNICEF social media guide for more information!

Think and Ink: Your Favorite Websites and Platforms

Circle the social media platforms you interact with most. Use the fill in the blanks for additional ideas!

 Twitter	 Facebook	 Instagram	 TikTok
 YouTube	 WhatsApp		



Teamwork in Advocacy

Teamwork is a great way to achieve a common goal, allowing for advocates to engage in **joint advocacy**. Advocates working on a team are more likely to draw attention that results in positive and sustainable change.



Photo: Elizabeth Glaser Pediatric AIDS Foundation, Kevin Ouma, 2021



Joint Advocacy

Joint advocacy is joining with others in any action that speaks in favor of, recommends, argues for a cause, supports or defends, or pleads on behalf of others.

Take Note!

In teamwork, advocates share...

- information
- opportunities
- skills
- and resources



...all of which can help build collective action and power!



Think and Ink: Teamwork

Using the note section at the bottom of this page, list potential groups and other people to bring into your team!



Successful teamwork is built on trust, respect, and a commitment to working together. Successful teams share several traits, including:



Clear Goals

- Team members reach a common goal and understand who will benefit from their work.



Diverse Membership

- Team members relate to the issue that is being advocated for and represent various perspectives.



Participatory Processes

- The team has processes for open and inclusive decision making, such as group discussion, procedures for conflict resolution, and makes sure all members' voices are heard.



Trusting Relationship

- Teams need members who are open and trust each other. This trust helps the teamwork through any disagreements that might happen. Trust can be built through ice breakers, group discussions, social events, and open decision making.



Balance of Identity

- Sometimes team members must sacrifice their own priorities for the joint interests of the team. Leadership must ensure there is a balance, so team members maintain their own identity and independence but remain committed to the common cause.



WHAT'S NEXT?

Congratulations, you are now ready to advocate! Here are some next steps to keep in mind as you begin this important work.

Find a place to start

Advocacy can feel overwhelming, so think about one way you can start to advocate in your community. You are a Breakthrough Champion and are ready for advocacy!

Ask the 5 key advocacy questions

Answering these questions will help you plan to address the issues that you are seeing in your community and will guide you through the advocacy process to make sure you are approaching a challenge in an organized way. Use the template on page 14 to create your own advocacy plan.

Reach out to an advisor

If you don't know the answer to a question, reach out to the Breakthrough Partnership Advisor in your country – they are here to help you! Advocates do not need to know the answer to everything and often rely on others to share knowledge and experience as well.

Partner with others

Look for opportunities to partner with peers or other advocates. There are many people who want to work together with you to make a difference. You are stronger working together than trying to do everything alone.

Share your story and messages

Practice sharing your story and messages. You are the expert about your own lived experience, and this story is important to tell to individuals with power. Speak with your peers and others that you work with to make sure you are effectively communicating your message.

Document

Make sure to document your advocacy experiences! You can share your story and successes via social media and other means of communication. Your advocacy can inspire others to become a champion as well!



Photo: Elizabeth Glaser Pediatric AIDS Foundation, Ricardo Franco, 2022