

PROMOTION & DISSEMINATION TOOLKIT FOR

DIFFICULT DECISIONS: A Tool for Care Workers

Managing Ethical Dilemmas When Caring for Children and Families of Key Populations:
People Living With HIV, People who use Drugs, Sex Workers, Transgender People, Gay Men, and other Men who
have Sex with Men

Help Spread the Word:

Ethical Decision-Making Guidance Will Help Care Workers and Improve the Lives of Key Populations & Their Children

An international working group has filled a global programming gap with the release of a tested and validated ethical decision-making tool for use in community-based HIV organizations. The tool, called 'Difficult Decisions' is the result of a rigorous three-year process, and is designed for an employee or peer support worker to use when faced with an ethical dilemma. But it was designed—in consultation with leading ethicists—by populations uniquely affected by HIV: people who use drugs, sex workers, transgender people and gay men or other men who have sex with men. And, notably, it includes reference to dilemmas involving their children.

We need you to help publicize and disseminate the tool.

Here's how you can help:

1. Join the conversation on social media

- Post about “Difficult Decisions” on **Facebook** and **Twitter**--especially between July 18th and July 25th 2014. Use the hash tags and messaging provided.

2. Send an email to your contacts, and share the link to the guidance

- Use the email text provided in this toolkit, and adapt it in your own voice
- Send the link to where the guidance can be downloaded – www.careworkerethics.org, or the short url bit.ly/1l0zWjv

3. Send the press release -- in this toolkit -- to your media contacts

4. Write a blog or newsletter article about the guidance, adapting text from the materials in this toolkit

5. Distribute the promotional flyer at AIDS 2014 (use the French, Spanish or Russian version where appropriate. The pre-design version is available as part of this toolkit; the designed version is in a separate document)

6. Use the Spanish, French or Russian versions of the appended documents – contained in a separate file – where appropriate.

SOCIAL MEDIA TOOLKIT

Social Media Toolkit to Promote “Difficult Decisions”

Add to the conversation by using #EthicalDecisions and sharing information about “Difficult Decisions” on Twitter and Facebook.

Use the official hash tag:
#EthicalDecisions

Other relevant hash tags and addresses:

#DifficultDecisions #ethicsmatters #ethicaldilemmas #FourStepTool #children
#trans #sexworkers #drugusers #LGBT #keypopulations #MSM
#globalvillage2014 #AIDS2014 #HIV #PLHIV

Organizations to follow on Twitter: @gnpplus @inpud @GlobalSexWork @msmgf @theaidsalliance
@AIDS_conference @GVAIDS2014

Suggested Tweets:

- Please RT! #EthicalDecisions matter in HIV care. This new tool can help reduce stigma www.careworkerethics.org #keypopulations
- #HIV care workers face #ethicaldilemmas. A new tool helps them treat #keypopulations more fairly. bit.ly/1I0zWjv #EthicalDecisions
- This #FourStepTool will help #HIV workers handle #ethicaldilemmas when serving #sexworkers #drugusers and their kids. bit.ly/1I0zWjv
- Please RT! This #FourStepTool bit.ly/1I0zWjv- will help #HIV workers with #ethicaldilemmas when serving #MSM #PLHIV #trans people etc

Suggested Facebook posts:

- Exciting new tool helps care workers in HIV handle ethical dilemmas when dealing with key populations and their children, i.e. people living with HIV, people who use drugs, sex workers, transgender people, gay men, and other men who have sex with men. It’s been tested in high, medium and low-income settings, in four languages – and was developed by key population groups, ethicists, and care workers in collaboration. See this link to download the guidance in English, French, Spanish or Russian. www.careworkerethics.org
- At the International AIDS Conference – AIDS2014 in Melbourne, we’ve launched a guidance and Four Step Tool to help care workers in HIV handle ethical dilemmas when dealing with key populations and their children, i.e. people living with HIV, people who use drugs, sex workers, transgender people, gay men, and other men who have sex with men. It’s been tested in high, medium and low-income settings, in four languages – and was developed by key population groups, ethicists, and care workers in collaboration. See this link to download the guidance in English, French, Spanish or Russian. www.careworkerethics.org
- Care workers in HIV care face ethical dilemmas at least weekly if not daily, according to a global survey done last year. Now there’s something that can help. There’s a new guidance and Four Step Tool called “Difficult Decisions” to help care workers in HIV handle ethical dilemmas when dealing with key populations and their children, i.e. people living with HIV, people who use drugs, sex workers, transgender people, gay men, and other men who have sex with men. See this link to download the guidance in English, French, Spanish or Russian. www.careworkerethics.org
- Let’s face it: ethical dilemmas happen frequently in HIV care. People living with HIV, people who use drugs, sex workers, transgender people, gay men, and other men who have sex with men deserve better for themselves, and for their children. A new tool helps reduce stigma for key populations, and helps care workers feel better about their decisions because they’ve treated key populations more fairly. It’s been tested in high, medium and low-income settings, in four languages – and was developed by key population groups, ethicists, and care workers in collaboration. See this link to download the guidance in English, French, Spanish or Russian. www.careworkerethics.org.

EMAIL TEXT

Email header: **Difficult Decisions: An ethical decision-making tool for care workers**

Dear XXX,

I know that ethical decision-making matters to you. It matters to all people with HIV, including key populations and their children, and it matters to care workers who want to do the right thing.

I'm therefore very pleased to be pointing you to a highly anticipated guidance and simple "Four-Step Tool" to support care workers to resolve difficult ethical dilemmas that they often face in their work.

Difficult Decisions: A Tool for Care Workers Managing Ethical Dilemmas When Caring for Children and Families of Key Populations:

People Living With HIV, People who use Drugs, Sex Workers, Transgender People, Gay Men, and other Men who have Sex with Men

This guidance, available in English, French, Spanish and Russian, was developed by an international working group led by key population networks, and comprising community-based ethicists & care worker organizations. It was tested, improved and validated in four languages and five countries—in Africa, Asia, Eastern Europe and North America—over a rigorous 3-year process.

Go to www.careworkerethics.org to download the guidance and its supporting documents, which include:

- "Difficult Decisions" – the comprehensive guidance written in plain language—in PDF format—containing the Four Step Tool, a Code of Ethics, 3 examples of ethical dilemmas resolved using the tool, and a Pocket Guide to Handling Ethical Dilemmas in the Field – printer layout;
- "Difficult Decisions" – "booklet" layout (2-pages side by side);
- A stand-alone, editable MS Word Document containing The Four-Step Tool
- Orientation Slides (PowerPoint format) to help you deliver a 3-hour orientation to your colleagues, and to implement the use of the guidance in your organization.

I hope you'll find this tool useful. [Optional: As a member of the working group that developed this guidance, I would be grateful if you would please let us know how it has supported your work or affected the quality of life for you and your peers.]

Sincerely,

XXXX

PRESS RELEASE

For Immediate Release

Contact: John Miller, john.miller@ccaba.org, +1-416-574-1765

New Simple Tool Developed to Manage Ethical Dilemmas in HIV Care Fills Global Programming Gap in Work with Children and Families of Key Affected Populations

July 21, Melbourne, Australia — An international working group has filled a global programming gap with the release of a tested and validated ethical decision-making tool for use in community-based HIV organizations.

The tool, called ‘Difficult Decisions’ is the result of a rigorous three-year process, and is designed for an employee or peer support worker to use when faced with an ethical dilemma. But it was designed—in consultation with leading ethicists—by populations uniquely affected by HIV: people who use drugs, sex workers, transgender people and gay men or other men who have sex with men. And, notably, it includes reference to dilemmas involving their children.

Jude Byrne, Chair of the International Network of People Who Use Drugs, said, “We know those who work with people who use drugs face distressing dilemmas, but these are *our* lives that hang in the balance, as well as the lives of our kids.”

Pointing to the four-step tool that leads a care worker through a careful process of weighing all the options, she went on to say, “Hopefully, people who use this tool will make decisions that do the most good, or at the very least that do the least harm. This tool will make sure they treat us and our children with dignity, and that they leave their bias at the door.” Bias, for instance, about who can and should be a parent. About who can make decisions for themselves. Or even about who deserves high-quality HIV treatment or care—issues that all the groups involved in the project have faced in some way.

The guidance is being released at AIDS 2014, the International AIDS Conference taking place in Melbourne, Australia. Ms. Manohara Subramaniam, who works with the a care organization Malaysian AIDS Council, feels this tool could have as much impact as some of the conference’s scientific advancements. “As a care worker, I can tell you, these decisions weigh on us. We sometimes wonder if we’ve done more harm than good. It can lead to burnout and staff turnover. This tool will help our workers to feel more confident about their decisions. About the *rightness* of their decisions.”

The tool is part of a larger guidance explaining ethics and ethical decision making to those less familiar with the concepts, and is accompanied by orientation slides and a handy pocket guide for more urgent in-the-field decisions. It is available for download from www.careworkerethics.org.

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An international working group spearheaded the design of Difficult Decisions: A Tool for Care Workers Managing Ethical Dilemmas When Caring for Children and Families of Key Populations -- People Living With HIV, People who use Drugs, Sex Workers, Transgender People, Gay Men, and other Men who have Sex with Men. For more information, please contact John Miller of the Coalition for Children Affected by AIDS, at +1-416-944-1765 or visit either www.ccaba.org or www.careworkerethics.org.

Q's and A's

Difficult Decisions: A Tool for Care Workers

Managing Ethical Dilemmas When Caring for Children and Families of Key Populations:

People Living With HIV, People who use Drugs, Sex Workers, Transgender People, Gay Men, and other Men who have Sex with Men

Q: Where can I find “Difficult Decisions”?

A: You can download the guidance, and the stand-alone worksheets, as well as some orientation slides, from the following website: www.careworkerethics.org

Q: Who is “Difficult Decisions” for?

A: The tool is intended for any care worker—a person who may be a staff member, a professional, a government service provider or a volunteer who has a role as a helper, carer, counsellor, clinician or personal advocate.

Small to medium-sized community-based care, treatment or support organizations that traditionally do not have an ethics program will find this guidance particularly useful, but the decision-making tool has been tested and shown to work in a variety of settings, including in health care.

Q: Can people with HIV and other key populations use “Difficult Decisions”?

A: Many PLHIV and members of key affected populations work in care and support roles, either as organizational staff or as peer support workers. In that capacity, they will find this tool useful. However, all members of key populations can bring this tool to the organizations that provide services to them, and advocate for the use of this tool to help make better, fairer decisions.

Q: How do I know this tool works?

A: *The Four-Step Tool* was adapted for this guidance from a tool developed and shown to work in situations encountered by home health and support workers in very poor, immigrant communities in Canada. The working group that wrote this guidance adapted the tool for an international context, and for one specifically dealing with situations involving key populations and their children. Furthermore, the tool was piloted in five countries, and refined based on feedback. The pilot findings showed that it a) helped care workers to make decisions and feel more comfortable with those decisions, and b) helped care workers to identify and question their own biases in providing care. An evaluation of the tool's effectiveness and impact is currently being conducted in sites in Australia, Lebanon and Kenya.

Q: I'm a member of a key population and my biggest problem is stigma and discrimination from care workers. Will this tool help me?

A: Stigma is a huge problem, and this tool won't solve it on its own. However, it was specifically designed to prompt care workers to question whether or not they are making assumptions based on bias as part of their decision-making process. It also prompts care workers to consult with clients at every stage of a decision. Furthermore, it contains a code of ethics that the user is encouraged to follow.

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It is possible that, even when using this tool, a care worker will make a decision that you will not agree with. However, care workers who use the tool are expected to consider which choices will cause more good than others and which choices may cause harm, and to justify what they choose to do. To quote from the guidance: “Fairness demands that we must be able to justify our decisions and actions with reasons, and sensitively explain why and how we made our decision to those affected, particularly when asked.”

Q: My organization doesn't work with key populations, or see children very much. Will this tool work for the kind of dilemmas that I come across in my work?

A: The methodology is completely transferable to other situations in health and social service settings—even settings not involving children, key populations or HIV.

Q: I might want to introduce this to my organization. How do you recommend I go about it?

A: Start with getting buy-in from a manager or colleagues. Show them the guidance. Once you have approval, slides have been created to assist you in providing an orientation to your colleagues, including 1) an introduction to what is ethics and what is an ethical dilemma, 2) how to use the Four-Step Tool, and 3) how to implement the use of the tool in your organization. See www.careworkerethics.org to download slides

Q: I have a huge caseload and don't have time to stop and complete long worksheets. Is this kind of tool for someone like me?

A: Completing the tool does take time, but it is intended for use in the most difficult of ethical dilemmas, ones that you cannot easily solve on your own. It may be that occasionally you have to slow down to solve a very difficult ethical dilemma. Over time, you may find you can do this more easily and more quickly. For situations that are time-sensitive or where a decision has to be made quickly in a person's home, on the street or at an appointment, there is a set of field questions on the last page of the guidance: a *Pocket Guide to Handling Ethical Dilemmas in the Field*.

Q: Some of the ethical dilemmas in the guidance seem extreme, while others seem simple to solve. How did you come up with them?

A: All of the ethical dilemmas are based on real situations that were shared with the working group as part of a global consultation, or encountered/experienced by members of our working group. While one ethical dilemma might seem easy to solve for one person, another person might find it very difficult. Also, for one care worker, a situation might seem extreme, while for another, the situation may seem commonplace—it all depends on the person's circumstances.

Q: How did the working group come up with the Four-Step Tool and the Code of Ethics?

Q's and A's

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A: The *Four-Step Tool* was adapted for this guidance from a tool developed and shown to work in situations encountered by home health and support workers in very poor, immigrant communities in Canada. The working group that wrote this guidance adapted the tool for an international context, and for one specifically dealing with situations involving key populations and their children.

The Code of Ethics was developed and adapted by the working group based on similar codes of ethics found in its research.

Q: How do I know that this will work in my region? Is it really possible to create a tool that works in all regions and in many languages?

A: The tool has been tested in English, Spanish and Russian—in Africa, Eastern Europe, Asia and North America. It has been shown to work in high, middle and low-income settings, and across languages.

Q: There are very clear laws and policies that our organization must follow. I'm not sure there's any room for me to use this tool.

A: Sometimes the law or policies may appear to conflict with what we believe is the right thing to do. The purpose of the tool is to provide us with a framework for decision-making when conflicting values, beliefs, responsibilities, or concerns pull us in different directions, and we are trying to make a decision that does the most good or the least harm—in other words, a decision that is ethical.

Q: I make my decisions based on a human rights framework. I'm not sure how this tool can help me.

A: There may be times when respecting one person's rights means that we cannot respect the rights of another person. Human rights are a necessary starting point for how we should act, but they cannot tell us how to act when we face ethical dilemmas.

In these situations, we need a method for working through the competing values and conflicting interests. The *Code of Ethics* contained in 'Difficult Decisions', as an important part of the ethical decision making tool, helps us to do just that.

Q. Is there anyone I can contact about the tool?

A: If you wish to contact the authors of the tool, please go to www.careworkerethics.org. The name and the contact information for one of the working group leads are listed there.

DIFFICULT DECISIONS: A Tool for Care Workers

Managing Ethical Dilemmas When Caring for Children and Families of Key Populations:
People Living With HIV, People who use Drugs, Sex Workers, Transgender People,
Gay Men, and other Men who have Sex with Men

When it comes to HIV care and support, making better decisions matters to all of us.

Ethical decision-making:

It matters to all people with HIV, including key populations and their children; and it matters to care workers who want to make the best possible decision.

If you want to make the best possible decision—or wish that the organization that supports you would improve its decision-making—now there's a simple tool that can help.

This guidance and tool—available now in English, French, Spanish & Russian—was:

- Developed by an international working group led by key population networks and comprising community-based ethicists & care worker organizations.
- Tested, improved and validated in four languages and five countries—in Africa, Asia, Eastern Europe and North America—over a rigorous 3-year process.

Downloads include:

- A comprehensive guidance written in plain language—available in PDF—containing the Four Step Tool, a Code of Ethics, 3 examples of ethical dilemmas resolved using the tool, and a Pocket Guide to Handling Ethical Dilemmas in the Field.
- A stand-alone, editable MS Word Document containing The Four-Step Tool Orientation Slides (PowerPoint) to help you deliver a 3-hour orientation to your colleagues, and to implement the use of the guidance in your organization.

Download *Difficult Decisions* now, in English, French, Spanish & Russian, from:

www.careworkerethics.org