






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

2014

Difficult Decision: 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

Principal authors: Ibarra, Kimberley; Miller, John; Wagner, Frank
Graphic designer: Thorpe, Michelle

For more information, please contact The Coalition for Children Affected by AIDS – www.ccaba.org.

To download additional copies of this guidance, an orientation slide presentation, and an editable MS Word version of the Four-Step Tool, please go to www.careworkerethics.org.

TABLE OF CONTENTS

IMAGINE... For the past three months you have been caring for a single father and his fifteen-year-old daughter. The father and daughter are both HIV-positive. The father has been coming to your organization regularly for counselling and HIV-related antiretroviral therapy (ART).

Recently, the father has missed his regular appointments at your organization, so you decide to visit the family at home to follow up with him and make sure that everything is all right. When you go to the home, you find out that the father has been taking his daughter's medication.

You try to counsel him about the importance of both of them taking the proper medication, but he dismisses your concerns.

He asks you to leave and tells you that he knows best for his daughter, and he'll get her medication when she needs it.

How will you decide? What should you do?

IMAGINE... You work with a family whose ten-year-old child is HIV positive. The child asks you whether he is sick and why you are giving him medicine. **The family has told you that under no circumstances are you to tell the child about his status.** You wonder whether the child should be told the truth, but you also do not want to break the family's trust in you.

If you tell the child the truth, the family may never trust you again. If you don't tell the child the truth, you may be missing an opportunity to educate him about HIV.

What other options do you have? How might you support this child? How might you support this family?

How will you decide? What should you do?

In every country, there are people living with HIV, people who use drugs, sex workers, transgender people, gay men, and other men who have sex with men who experience stigma, abuse, criminalization and/or marginalization—as do the children of these groups. In this document, we refer to these groups as 'key populations'. This means that they are the key populations that are affected by HIV, and our focus is mostly on scenarios that involve children and families. These groups are often denied the basic human right to receive responsive, respectful and high-quality social and healthcare services. As a result, these groups are at a greater risk of having poor health, and as groups of people, they have HIV infection rates that are much worse than in the general population. In these circumstances, children become more vulnerable.

Care workers who serve children and families of key populations often face difficult challenges and ethical dilemmas. ***This is especially true when moral, religious or personal belief systems—compounded by laws, systems and institutions—result in bias or judgement about these key populations***.

Sometimes biases or judgements can be related to a person's health situation, as in the case of children and adults living with HIV. Other times, they can be related to a person's identity, as in the case of transgender children and adults, or gay adolescents and men, or to behaviour, as in the case of people who use drugs or men who have sex with men. Or, biases or judgements can be related to a person's occupation, as in the case of sex workers, and by extension, to the children of sex workers. Bias has an impact on people's dignity and their right or ability to receive good care, treatment or support, or to be integrated fully into our communities.

Care workers want to do the right thing, but under difficult circumstances, may need support to do so. A global consultation conducted by the working group developing this guidance and tool clearly identified the need to help care workers not only to distinguish personal views from professional obligations but also to make difficult decisions in a manner that is ethical, and does the most good or the least harm.

The tool is important to care workers because it allows them—through following a logical step-by-step process—to think about and discuss how decisions can be influenced by our environment, and by personal biases and judgements about key populations, whether they are children or adults. This tool is important to key populations because it is a way to identify and minimize the harm and stigma that clients experience when receiving care.

This guidance was prepared with input from global advocacy groups, care workers, and care worker organizations working in Africa, North & South America, Western, Central & Eastern Europe, the Caribbean, and Asia-Pacific (including Central Asia). The authors hope that using this tool will contribute to improving the lives of children and families receiving care, treatment, and support.

Instructions:
Using The Four-Step Tool to Decision-Making

Ethical decision-making is a process that helps us to look carefully at the ethical dilemmas that we face so that we can decide and explain what we should do, why we should do it, and how we should do it. Ethical decision-making starts when we recognize that we are facing competing values and helps us answer the question: ***"What should I do?"*** Often, it is about making the best possible choice when two or more options are available.

The four-step tool to ethical decision-making ('The Four-Step Tool') guides people through a step-by-step process of resolving an ethical dilemma. The steps take into account the facts, ethical principles, various alternatives and their potential consequences, and an evaluation of the outcomes.

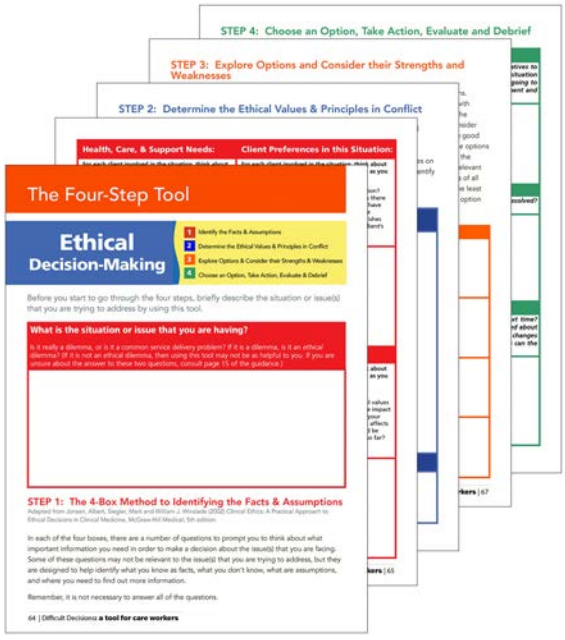
When not to use the tool:

This tool is not for use in time-sensitive situations. In situations where a decision has to be made quickly in a person's home, on the street or at an appointment, *see the set of field questions on page 69.*

Also, this tool is meant to help us with ethical dilemmas, not with common service delivery problems or with ordinary dilemmas that don't involve an ethical situation. For help understanding the difference between these three kinds of problems, see page 15 or consult the glossary.

In this guidance, ethical decision-making involves these four steps:

1. Identifying the facts surrounding the decision, being careful to separate assumptions and to verify them;
2. Determining why this is an ethical dilemma, which means determining what values, beliefs, responsibilities, or concerns are pulling us in different directions using the Code of Ethics;
3. Exploring the different options, and what is good or bad about each option; and
4. Making a decision—in other words, taking action, based on which option does the most good, or the least harm.



Step 1: The 4-box method to identifying the facts and assumptions

The purpose of this section is to identify what we know, what we don't know, what is an assumption, what is a judgement, what is based on bias, and what is an emotional reaction. This helps us figure out what is really going on. Using the questions in the four boxes, users are prompted to take into account all of the relevant considerations and

stakeholders. This often leads to uncovering facts that may not be known at first, or discrediting assumptions that were initially seen as facts.

An important part of this step is reflecting on one's emotions, feelings, and values as they may influence how one responds or reacts to a particular situation. It is important for us as care workers to be aware of such emotions/values/biases, and to act accordingly. For example, if we cannot remain objective, we should remove ourselves from the situation and ask a peer or manager to become involved.

It is also important to consider the thoughts, emotions, and cultural traditions of the person to whom you are providing care and other relevant stakeholders—family, children, or other caregivers, etc.—as this can help you further understand the issues. This should involve talking to the client(s) about the situation and asking what they want, unless it would cause more harm to the client(s) to do so.

> It is not important that we put this information in the right box, since the boxes are related to each other. Also, it is not necessary to answer every question. What matters is that we identify the important information that we need to help us make a decision.

Step 2: Determine the ethical values and principles in conflict

Identifying the ethical values and principles in conflict will not provide solutions; however, this step will help further clarify and identify the ethical dilemma. In this step, we determine which values, responsibilities or concerns are pulling us in different directions. We may find that there is no ethical dilemma (e.g., that it is purely a programming issue). In this case, the decision-making tool can still be applied to help resolve the issue. To help complete this step, we use the Code of Ethics, which appears on pages 16-18 of this guidance. The code of ethics has ethical principles that we think are important and help guide our actions. We can use it as a common language to talk about ethical dilemmas and why we are unsure of what to decide.

Step 3: Explore options and consider their strengths and weaknesses

Explore the different options and consider their strengths and weaknesses. Think about different options and consider the potential outcomes and impacts of each one—evaluate the pros and cons of each option. To help complete this step, we use the facts from step one to identify what is practical about the options, and the ethical values and

© Marcela Nievas / Alliance

principles from step two to identify what is ethical about the options. Looking critically at options helps us decide what we should do and why we should do it.

When thinking about strengths, think about things like what ethical principles each option prioritizes or upholds, and how easy each option is to implement using the ethical principles from step 2 and the facts you identified in step 1. When thinking about weaknesses, think about things like what ethical principles each option violates and how hard it would be to implement them in real life. Rate each option based on the degree of its advantages and disadvantages by weighing the ethics and how practical each option is.

Step 4: Choose an option, take action, evaluate and debrief with colleagues

The last step is to make a decision and act on it based on which option(s) have the highest degree of advantages compared to disadvantages, not necessarily the one with the highest number of pros or the lowest number of cons. This might mean the option that does the most good, or the least harm, or it could be the option that avoids acting wrongly. Involve the client(s) in choosing from the options, unless it would cause more harm or undue burden to do so—for example, if telling the client(s) the different options would make them extremely upset or feel betrayed (whether to or how to involve the client(s) can be an ethical dilemma in and of itself).

Develop an action plan and document what you are going to do. Also decide how to communicate this plan to the client(s) and other relevant stakeholders to maximize their understanding and acceptance of the plan. Ongoing communication is very important.

Next, evaluate what happened. Did you obtain the results you intended? Is more follow-up or action needed? Could it be helpful to include other services or service providers that are sensitive to this population? Self-evaluate to reflect on the decision-making process and outcomes achieved, and your own feelings about the situation. Reflect on whether organizational change is needed to address these situations in the future.

© UNICEF, Ukraine, 2010, G.Pirozzi

The Four-Step Tool

Ethical Decision-Making

1. Identify the Facts & Assumptions
2. Determine the Ethical Values & Principles in Conflict
3. Explore Options & Consider their Strengths & Weaknesses
4. Choose an Option, Take Action, Evaluate & Debrief

Before you start to go through the four steps, briefly describe the situation or issue(s) that you are trying to address by using this tool.

What is the situation or issue that you are having?

Is it really a dilemma, or is it a common service delivery problem? If it is a dilemma, is it an *ethical* dilemma? (If it is not an ethical dilemma, then using this tool may not be as helpful to you. If you are unsure about the answer to these two questions, consult page 15 of the guidance.)

STEP 1: The 4-Box Method to Identifying the Facts & Assumptions

Adapted from Jonsen, Albert, Siegler, Mark and William J. Winslade (2002) Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine, McGraw-Hill Medical; 5th edition.

In each of the four boxes, there are a number of questions to prompt you to think about what important information you need in order to make a decision about the issue(s) that you are facing. Some of these questions may not be relevant to the issue(s) that you are trying to address, but they are designed to help identify what you know as facts, what you don't know, what are assumptions, and where you need to find out more information.

Remember, it is not necessary to answer all of the questions.

Health, Care, & Support Needs:

For each client involved in the situation, think about the following questions, and answer as many as you think relevant:

What do you think the client's needs are (e.g., health including treatment and medications; care; support; social needs, etc.), and are there other people whose needs should be considered? What about potential risks and harms? What other facts do you need? Be careful about unduly consulting with family or medical personnel who may, or may not have the best interest of the client in mind.

Client Preferences in this Situation:

For each client involved in the situation, think about the following questions, and answer as many as you think relevant:

Have you talked to the client about this situation? What are the client's expressed preferences? Is there any reason to believe that the client does not have the ability to make decisions? If yes, who is the substitute decision maker? If no, are client's wishes informed, understood, and voluntary? Is the client's right to choose being respected?

Quality of Life:

For each client involved in the situation, think about the following questions, and answer as many as you think relevant:

How has the client described the current situation to you in the context of life generally? What would it mean to the client if you could meet the needs and preferences described? What difference would it make in the client's life? As a care worker, do you see it the same way? Consider emotions, feelings, values, biases and prior experiences of the people involved, including you. What are the consequences for you in supporting the client's preferences?

Contextual Issues:

For each client involved in the situation, think about the following questions, and answer as many as you think relevant:

What is the relevant social, economic, and/or institutional context? Are there organizational values to consider? What laws might have a negative impact on your client(s)? What laws might influence your response? Has anything changed recently that affects the situation? What other services are or could be involved? What plans have been put in place so far?

STEP 2: Determine the Ethical Values & Principles in Conflict

Now that you've identified the facts, identify the ethical dilemma(s). Which ethical principles are in conflict?

Refer to the list in the left column and to the full Code of Ethics and Ethical Values and Principles on pages 16-18. It may help to explain the issue(s) first by using the facts from Step 1, and then to identify the ethical values and principles that correspond to the issue(s). State the ethical dilemma by explaining which ethical values and principles are in conflict – there may be more than two.

Circle the relevant ethical values & principles below:	**Explain the Issue(s):**
• ***Dignity*** • ***Diversity*** • ***Advocacy*** • ***Security*** • ***Quality*** • ***Accountability*** • ***Privacy*** • ***Confidentiality*** • ***Managing Conflicting Obligations*** • ***Fair and Equitable Access*** • ***Health and Wellbeing*** • ***Informed Choice*** • ***Empowerment*** • ***Cooperation*** • ***Family*** • ***Prioritizing children while supporting parents in key populations***	
Based on Steps 1 & 2, what is/are the ethical dilemma(s)?	

STEP 3: Explore Options and Consider their Strengths and Weaknesses

Brainstorm all of the options that you can think of, even those that may not be ideal solutions. Brainstorm and discuss with peers as appropriate. Whenever possible, discuss the options with your client(s). Consider under what circumstance(s) you would not discuss the options with the client(s), and how you would justify that decision. Be creative and use your imagination. Consider a compromise. Think about the outcomes or consequences for each alternative. What is the good that might come of each option? What is the harm that might come of each option? Do the options you have developed fit with the client(s)'s/family's statement of values and preferences, and the information that you obtained from your client(s)? Question whether the alternatives meet relevant policies, directives and regulations. Make sure that you weigh the strengths and weaknesses of all of the options before you make a decision. Consider which options do the most good or the least harm. Consider what ethical principles each option upholds or what ethical principles each option violates. Consider also how practical it would be to act on each option.

Option:	Strengths:	Weaknesses:

STEP 4: Choose an Option, Take Action, Evaluate and Debrief

Develop an Action Plan *(The actual plan should be documented)*

Given all the information that you have, choose the best option(s) available. Present alternatives to the client(s) and those involved. Re-examine the options if other factors come to light, if the situation changes, or if the client does not agree. Develop an action plan that includes what you are going to do and the steps that you are going to take. Determine when to evaluate the plan. Document and communicate the plan.

THE PLAN IS:

Evaluate the Plan:

What was the outcome of the plan? How did the client(s) feel about how the issue was resolved? Is there need for further action?

Self-evaluate Your Decision and Debrief with Colleagues:

How do you feel about the decision and the outcome? What would you do differently next time? What would you do the same? What have you learned about yourself? What have you learned about this decision-making process? What can your organization learn from this situation? What changes can the organization make to better support people making similar decisions? What changes can the organization make to better address these types of situations?

What is Ethics, and What is an Ethical Dilemma?

Ethics is about how we understand what is 'right' and what is 'wrong', and what is 'just' and what is 'unjust'—regardless of where we are from, where we live, our religion, gender identity, sexual orientation, culture, policies, or the law. Ethics is about asking, "What should we do?" when we face difficult choices. This is not the same as asking, "What does the law tell me to do?", "What does my organization tell me to do?" or "What does my religion, culture, or society tell me to do?"

IMAGINE... You are a care worker. **Your client who is HIV-positive and is not regularly taking his HIV medications tells you he is getting married.** He has been feeling much pressure from his family to find a bride. The wedding is happening in two months and his bride-to-be is a woman that you know well in social circles. Your client tells you they have not had sex yet, but that after the wedding, he and his bride plan to have a baby. **He asks that you not tell his fiancée that he is HIV-positive, or that he has occasionally had sex with men in the past. You worry that his viral load will make him infectious, that his bride will become infected with HIV, and that if she doesn't know her own HIV status, she may pass on HIV to their baby.** You repeatedly try to counsel him to tell his fiancée the truth, but he refuses, and will not consider breaking off the engagement. You will continue to counsel him to be strict about taking his medications, but his past history suggests he cannot easily stick to the regimen.

If you decide to keep his status private, his wife and child cannot determine whether they need treatment. **If you tell his wife so that she and their child can be tested, and (if needed) get treatment, you will be breaking his trust.**

Which decision is the right one? What other options might there be? **How should you decide?**

What is the difference between a problem, an ordinary dilemma, and an ethical dilemma?

This guidance is written to help solve a type of problem called an ethical dilemma, but there are other types of problems: common service delivery problems that do not involve dilemmas, and ordinary dilemmas that are not ethical in nature. Learning to distinguish between these three types of problems is important.

Service Delivery Problems

In providing care, support, or treatment, lots of problems can arise, but not all problems are dilemmas. For example, a service delivery problem that is *not* a dilemma is one where at least one of the options is desirable and will not lead to undesirable consequences.

The following scenario is an example of a common service delivery problem, i.e., a service delivery problem that is *not* a dilemma: A mother's young daughter is not listening to her and they are arguing a lot, but there is no situation of physical or emotional danger to the child. This is a common parental problem and even though finding a solution can be difficult, the level of difficulty does not make the problem a dilemma. In this scenario, there are strategies that you can try that will not make things worse in any way.

Dilemmas: ordinary dilemmas versus ethical dilemmas

A dilemma is a situation in which a difficult choice has to be made between two or more options that both appear to be equally *undesirable*. The options might be undesirable on their own, or they might be undesirable because trying one, and failing, eliminates the possibility of trying the other option.

It is important to understand that not all dilemmas are ethical dilemmas. In other words, some

© R.Srinivas Photovoice/ Alliance

dilemmas do not involve a conflict between *ethical* values or principles.

Ordinary Dilemmas

An example of an ordinary dilemma—one that does not involve a conflict between ethical values and principles—is having to decide between a) riding a bicycle to work on a rainy day and getting there on time but arriving with your clothes soaking wet, and b) taking public transportation to work and arriving dry, but arriving slightly late (in this scenario, there is no risk to being fired or docked pay for arriving late or arriving with wet clothes, but you will be seen as slightly unprofessional).

In this scenario, both options are undesirable, and there doesn't appear to be a third, desirable option. It is therefore clearly a dilemma. However, there is no conflict between ethical values or principles. Maintaining a perfect professional reputation by arriving at work on time and looking well dressed and dry may be a personal goal, but there is no ethical principle in this situation about doing the most good or the least harm to others.

Ethical Dilemmas

An *ethical* dilemma is a situation where 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. There are many examples of ethical dilemmas in this guidance.

Code of Ethics

We care for, support, and/or advocate for children and families affected by HIV including those from key populations: people living with HIV, people who use drugs, sex workers, transgender people, gay men, and other men who have sex with men. Many of the people that we care for are stigmatized and discriminated against because of who they are or what they do. We strongly believe that this is wrong.

All people, regardless of where they are from, where they live, their age, religious beliefs, gender identity, sexual orientation, culture, occupation, disability, social status, civil status, drug use, or serostatus are entitled to respect for their human rights, and should be treated and cared for with dignity[1].

Human rights, along with international, national, and local laws, and our organizations' policies are intended to guide us in what we should and should not do. But sometimes, we may face difficult situations where rights, laws, regulations, or policies do not provide us with enough guidance, or provide us with conflicting guidance.

There may be times when respecting one person's rights means that we cannot respect the rights of another person. Other times, we may be unsure of how to uphold these rights while following laws and policies, or the law or policies may appear to conflict with what we believe is the right thing to do. 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 like these. In these situations, we need a method for working through the competing values and conflicting interests. The Code of Ethics, as an important part of the ethical decision making tool, helps us to do just that. This code is not a list of rules, but a statement of the ethical values for those providing care, support, and/or advocacy to children and families of key populations affected by HIV.

It is also a code for how we believe we should behave as care workers when acting upon those values. It builds upon our universal human rights and identifies the ethical principles that may come into conflict when we are faced with ethical dilemmas. This code, along with the rest of our ethical decision making tool, helps us start to think about why some options or decisions are ethical, whilst other options or decisions are not.

Ethical Values and Principles:

Dignity:

- We believe that all people have value no matter who they are or what they do. We therefore strive to uphold and respect our clients' undeniable human rights.

Diversity:

- We believe that no one should be discriminated against because of their race, sex, age, gender or gender identity/ expression, beliefs, values, national origin, occupation, social standing, life circumstances, drug use, health status (including HIV status), sexual orientation, or any other sort of difference. We therefore strive as care workers to identify our own

[1]Most of these human rights can be found in the Universal Declaration of Human Rights (UDHR), International Covenant on Civil and Political Rights (ICCPR), International Covenant on Economic, Social and Cultural Rights (ICESCR), UN Convention on the Rights of the Child (CRC), Convention on Elimination of Discrimination Against Women (CEDAW), the Geneva Conventions, Convention on the Elimination of All Forms of Racial Discrimination (ICERD), the Convention on the Rights of Persons with Disabilities (CRPD), the International Conference on Population and Development (ICPD) Programme of Action and the Beijing Declaration and Platform for Action, the United Nations Joint statement on Ending Acts of Violence and Related Human Rights Violations Based on Sexual Orientation & Gender Identity, and the United Nations Declaration of Commitment on HIV/AIDS.

biases, to set those biases aside, to treat people as fairly as we can, and to celebrate the differences in our clients, and the different ways that they live their lives.

Advocacy:

- We recognize that our clients may be in difficult situations because of discrimination, stigma, poverty, criminalization of their behaviours, or ill health. Because they may not be in a position to act for themselves, or may need our help, we support our clients in combating injustices and human rights abuses. We also support their right to get external support if they feel they need advocacy to access *our* services.

Security:

- We believe that everyone—including our clients and those who care for them—deserves an environment in which they feel safe to live and work. We therefore condemn torture, violence, and any violation of a person's right to be safe, secure, and free from physical and psychological abuse.

Quality:

- We believe our clients deserve quality care and support services. We are therefore committed to providing them with the highest quality care possible, using the resources available to us.

Accountability:

- We believe we are all responsible for our actions and the consequences that follow them. As care workers, we must therefore not forget about the impact our choices have on our clients and on all the other stakeholders involved. We must also remember that, if we feel we must make decisions that our clients do not agree with, we must be able to justify our decisions with reasons, particularly when asked to do so, or when thinking later about why we made the decision.

Privacy:

- We believe that we should respect the personal boundaries and limits that our clients set and that whenever possible everyone should be in control of their own information and their physical person. We therefore take every measure to keep a client's personal health information private (see Confidentiality, below) unless consent is given to share it. Also, we commit to only touching and asking clients to undress as part of their being cared for and treated, and only if they agree to it.

Confidentiality:

- We recognize that our clients trust us to keep their information private. We therefore agree to do our utmost to prevent others from accessing our clients' information without their permission, and to make sure that this information is treated with the utmost care.

Managing Conflicting Obligations:

- We recognize that as care providers, there may be situations where our different obligations (to our organization, our clients, our own family, etc.) come into conflict, but that our clients' care should not suffer because of our obligations. As care workers, we strive to manage our conflicting obligations in a way that will not prevent us from acting in our clients' interests.

Fair and Equitable Access:

- We believe that if resources are scarce, treatment, care, and support should first be given to those most in need. We therefore strive, within our limitations, to serve the people most in need, regardless of who they are or what they do. We also strive to provide those people with the highest possible standard of treatment, care, and support that is free from bias and judgement.

Health and Wellbeing:

- We believe that people have the right to achieve the highest possible level of health and wellbeing, *as defined by them*. We therefore strive to provide our clients with care, treatment and support in a manner that

acknowledges what is important to them.

Informed Choice:

- We believe that our clients should be given what they need to make their own choices about their health care. We therefore strive to provide our clients with all the information they need to make a decision—and in an age-appropriate way for anyone under 18—such as a list of their options, the risks, and the potential benefits, with no details held back because of local taboo. We must also make sure that our clients can make their choices free from threats or intimidation.

Empowerment:

- We believe that when people have confidence and support systems, they can overcome fear and fight against discrimination and violence perpetrated against them based on who they are. We therefore support, wherever and whenever possible, the freedom of our clients to affirm their self-identity by participating in organizations and associations of their choice (e.g., those related to HIV, people who use drugs, sex workers, transgender people, gay men, and other men who have sex with men, or reproductive rights). We also support our clients' right to question the decisions made in caring for and supporting them, even if those decisions are or were made by us.

Cooperation:

- We believe that building cooperative working relationships among all stakeholders leads to the best possible care, treatment and support for our clients. We therefore strive to work together in the spirit of collaboration to maximize the effectiveness of the care that we provide.

Family:

- Because we believe that families have inherent value, we strive to support people to be parents or primary caregivers, and to live as a family, in the ways that they choose. When it comes to the opportunity to participate in family life, we strive to eliminate any extra restrictions on parenting and family life that might exist because of disease or disability, identity including gender identity, life circumstances including drug use, profession including sex work, sexual orientation or behaviour, or any other reason.

Prioritizing children while supporting parents or caregivers in key populations:

- Parents in key populations sometimes seek our support and advocacy to be the best parents that they can be. However, sometimes our work involves situations where the interests of an adult and the interests of a child appear to be in conflict. In these cases, we strive to base our decisions on the best interests of the child. We also believe that acting in the best interests of the child does not always mean calling the authorities to have a child removed from his or her family—even in some situations involving child safeguarding.

- We therefore strive, in prioritizing children, to consider carefully the immediate *and* long-term consequences to the child. We also strive not to let bias about the ability to parent or care for a child play a role in our decision.

- For instance, when we deal with key populations (such as people living with HIV, people who use drugs, sex workers, transgender people, gay men, and other men who have sex with men) our biases about their right or ability to parent can cloud our judgement about what is in the best interests of the child. A care worker who believes that it is inherently harmful for a child to be raised by a sex worker, for instance, has a biased, value-laden perception of harm that is not based on a real assessment of what constitutes risk, neglect, harm or abuse.

How do we make ethical decisions?

Ethical decision-making is a process that helps us to look carefully at the ethical dilemmas that we face so that we can decide and explain what we should do, why we should do it, and how we should do it. Ethical decision-making starts when we recognize that we are facing competing choices that involve ethical values or principles and helps us answer the question: ***"What should I do?"*** Often, it is about making the best possible choice when two or more options are available.

In this guidance, ethical decision-making involves these four steps:

1. Identifying the facts surrounding the decision;
2. Determining why this is an ethical dilemma, which means determining what values, beliefs, responsibilities, or concerns are pulling us in different directions, using the Code of Ethics;
3. Exploring the different options, and what is good or bad about each option; and
4. Making a decision - in other words, taking action, based on which option does the most good, or the least harm.

IMAGINE... You are working with a young transgender client who was recently told she is HIV positive. When you visit her at home, you find her in bed, shivering and very sick.

You think that she needs emergency medical care, but she is afraid of going to hospital. She tells you that she is undocumented and will be deported if anyone finds out, and she does not want to seek care because of terrible discrimination she has faced in the past just because of her gender identity.

You convince her to go to a local clinic with you and assure her that you will be there with her the entire time. At the clinic, you tell the staff that your client identifies as female, but when they see her identification card with a male gender marker, **the clinic staff refuses to address your client by her lived-in name or to use the pronoun that she prefers.**

Your client asks you to take her home and you understand why–even you were not prepared for the level of discrimination exhibited by the clinic staff. But if she leaves without receiving care, she may die at home.

You're unsure of what you should do. You want to respect your client's choices. She does not deserve to be treated the way they are treating her at the clinic - **she needs competent care urgently, but leaving the clinic may jeopardize her life and you worry that you can't risk her not getting any care at all.**

What other options do you have? How can you support this client? What should you do? **How will you decide?**

IMAGINE... You are a care worker with a medical background working at a non-profit community organization. Your organization works with several gay male clients who are terminally ill with AIDS, and who have been transferred to their homes from the hospital.

A few of your clients require injections and other medical care, but **they cannot afford to hire a nurse from a medical institution to provide this care in-home, and they do not want to return to the hospital because of the stigma and discrimination they experienced there.**

These clients are dying and need care and support, but you are unsure of what you should do in these situations. **You know that you could help these clients - your medical background means that you have been trained to give injections and other treatments. At the same time, the law in your country says that only medical institutions are allowed to provide medical care in people's homes.**

You cannot afford to lose your job and are afraid of going to jail. What should you do? How might you support these clients? **How will you decide?**

Who should use this guidance?

This guidance is for care workers—who may be staff members, professionals, government service providers or volunteers who have 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.

While it was developed primarily for use by care workers (people working directly with adults or children in a role providing care, clinical or professional services, counselling, support, helping or personal advocacy) it works best with the active support of management, and if those managers adopt the guidance for use with their team or with an entire organization.

Managers can use it as a tool to support their staff, and to identify gaps in program policy, training, supervision, or employee support.

We use real-life case studies of care workers who have worked with 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. Nonetheless, the guidance is applicable to children and families of other marginalized populations and to a much wider range of groups needing support.

How this guidance can help

Better, more consistent decisions.

Anyone who is a care worker knows that we face difficult decisions in our work—decisions similar to those in the stories we have gathered. A global consultation survey that we conducted in 2012 showed that care workers face difficult decisions at least once per week. In some cases, we face them daily.

© Alliance

Our work is challenging, and though we may mean well, our decisions can have a serious impact on the people that we are trying to help—and on their partners and children. They also put a strain on us, and can make our circumstances even more difficult.

Without this guidance, how would we usually make decisions?

- Sometimes we would look to policy, to our upbringing, or to the law.
- We might look to religion or to our cultural values. In some cases, we might act based on stereotypes and prejudice about the people we work with.
- Sometimes we would even guess, because any decision we make, even if we mean well, may result in harm to someone, and we don't know which decision is better or worse.
- Sometimes we might even avoid making a decision in order to avoid doing something that we believe is wrong.

Our regular process of decision-making can have a negative impact by:

- decreasing the quality of services that we provide,
- limiting access to services,
- breaking trust between workers and the people we care for,
- leaving us feeling upset or frustrated,
- resulting in stigmatization and discrimination against those we care for—even if that wasn't our intent,
- leaving those we care for feeling betrayed, or in the worst cases,
- causing mental illness or death.

The tool is:

- a simple, tested step-by-step method that any care worker can use to help work through decisions in a better, more consistent way;
- a methodology to address the ethical dilemma so that all parties have been treated fairly;
- a reminder to include recipients of care in conversations and in decisions that affect them—unless it would harm them or put an unfair burden on them;
- a way to determine whether we are doing more good and less harm; and
- a guide to help identify areas where our organizations need to be strengthened—either in changes to services, or improvements to program policy, staff skills-building, anti-bias training and protocols, staff supervision and support (including helping us to cope with *moral residue*), job descriptions, management training, or even staff recruitment procedures.

Not knowing if we did the right thing, or living with the negative consequences that came from our decisions can have an impact on us too. We feel distressed or uneasy when we are not able to do what we think is right and when we believe that the consequences of our decisions will actually harm the people we are trying to support. In the field of ethics, this is called 'moral distress'.

As care workers, we live with the consequences of those choices, and if our distress isn't dealt with properly, it can stay with us, becoming a serious burden. The burden we carry comes from not making what we thought was the right choice, or from having to act even though we know that the option we choose will cause harm. Some describe the experience as one where:

> "In the deepest part of yourself, you feel you will never be the same and you carry this with you for the rest of your life." [2]

In the field of ethics, this burden that stays with us—and its consequences—are called **"moral residue",** and if care workers are not supported in dealing with it, it can lead to 'burnout'—the feeling that we cannot continue to do the work anymore.

There are strategies for dealing with the moral distress and moral residue, for instance: making ethics part of our everyday work life, regularly stepping back to reflect on the rightness or wrongness of what we do, talking to our colleagues

© International HIV AIDS Alliance

about these issues in an open and supportive way, and regularly coming together as a group or as a pair to talk about what happened.

Another important way to avoid, prevent or lessen the distress and burden—and thereby to prevent burnout—is to use the tool in this guidance. By using it we will be able to assure ourselves that we have used a fair process to find the best answer possible, given the situation.

[2]McCarthy, J., & Deady, R. (2008). Moral distress reconsidered. Nursing Ethics, 15(2), 254-262.

Managing our expectations

This guidance and its tool can help but it is also important to understand its limits. For instance:

1. It is not a policy manual; it will not tell us what to do.

2. There is no perfect answer to most of these situations. Also, no method is perfect and sometimes, we make mistakes in applying a method.

3. In many organizations, especially ones that have fewer staff or less money, there is little support to help guide decision-making. So when we make a decision, we're not always sure if it was the right one.

4. The first course of action might not always work. We might have to re-evaluate the situation, and then try something else.

5. The solution, even if it is the right one, will likely be difficult. Some situations will still require difficult choices to be made—choices where one person's interests or rights may be prioritized over another person's, and these choices need to be justified. This tool will not eliminate all the difficult choices that we may face. However, it will ask us to consider which choices will cause more good than others and which choices may cause harm, and to justify what we choose to do.

6. This guidance aims to add another tool to our problem solving toolbox. It is not meant to replace all the other tools we have nor is it meant to solve every problem. Depending on the situation, certain tools will be more appropriate than others. For instance, while this tool may help us to identify the biases that we all have, and hopefully help us to set those biases aside, it will not eliminate stigma and discrimination. For that, clear policies and training are needed within organizations.

© Marcela Nievas / Alliance

7. Finally, this guidance does not guarantee that people will be happy with the decisions we end up making. Even if we *think* we are doing the most ethical thing, the people receiving care may not see it that way. It is not reasonable to expect that people will always understand or agree with our decisions, or with our actions. Still, 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.

Managing risk

© Absolute Return for Kids (arkonline.org)

Making a decision that is ethical involves risks: risks to the organization, to the worker, and even to the client. These risks need to be recognized and managed. We encourage:

1. Talking about the risks, including with clients;
2. Thinking carefully about what you record; and
3. Taking note of what impact the increased risks are having over time, and responding accordingly.

Considerations in working with
young children, adolescents under 18, and older youth up to 24

We urge you, in reviewing this guidance and in working through ethical dilemmas, to think of age-appropriate and culturally sensitive responses when dealing with children under 10, adolescents under 18, and older youth up to 24. For instance, a care worker dealing with issues involving a young child must consider different issues than a care worker who is supporting an adolescent. Some things to consider include:

1. Young people's legal rights as they get older;
2. The different ways one might protect or keep safe young children compared to adolescents;
3. The gender norms that often place unrealistic expectations on boys and girls, or gender inequalities in the household that place boys and girls at risk of harm (gender norms can also affect the way that boys and girls interact with care workers);
4. The role of the parent or guardian in the child/ adolescent's life;
5. That children or adolescents may be living with extended family, or with others;
6. Issues of adolescent sexual orientation or identity, or gender identity;
7. The kind of stigma or discrimination a child or adolescent might face;
8. Whether we want to or need to obtain consent when children or adolescents are living with their parent or guardian. In some cases, legal guardianship may not be clear;
9. How an organization might respond or provide service—or what other organizations or services might sensitively be able to help;
10. The capacity of children and youth to make decisions – within your legal context;
11. The child/adolescent's needs, rights, or wishes;
12. Children's decision-making capacity as they grow into adolescence;
13. The child/adolescent's health status;
14. The parent's health status; and
15. Other considerations.

IMAGINE... You are an outreach worker supporting migrant sex workers who are based in a brothel.

Your manager has received information that these women (including two of your clients who have young children) are victims of trafficking.

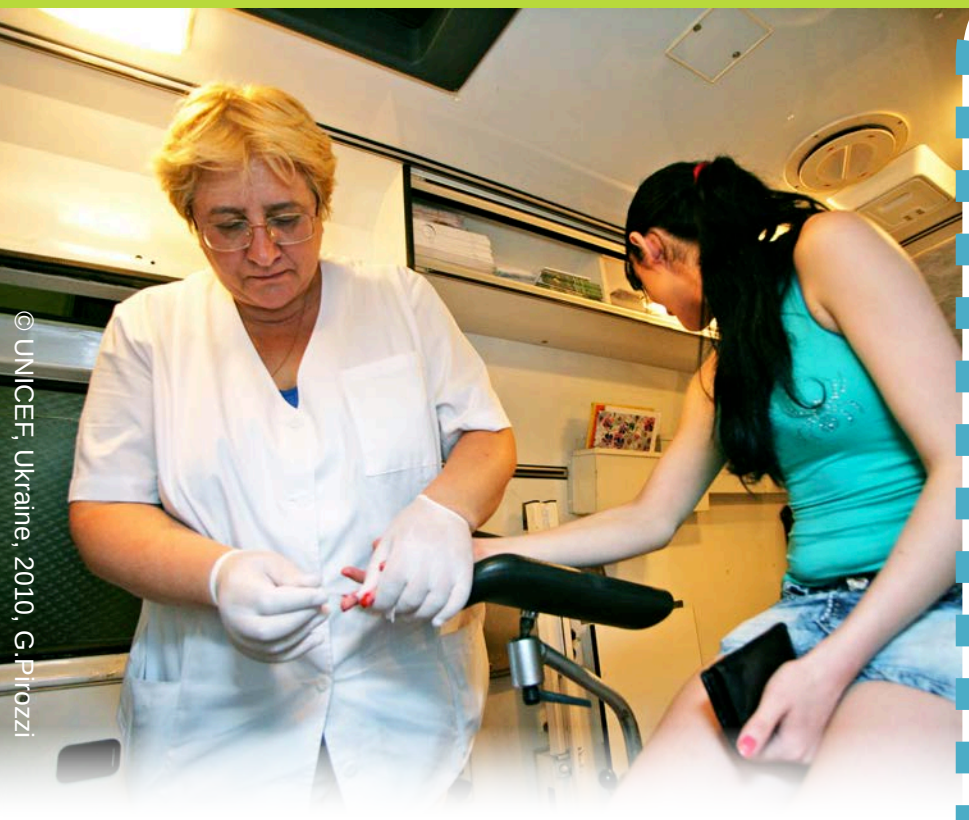
These women have not been asking you or your colleagues for help, despite the fact that you have been meeting with hem regularly. The women seem to have control of their own money and can travel freely.

The manager who received this information from an anonymous source has called a meeting to discuss reporting your clients to the police as suspected victims of trafficking and disclosing the address of the brothel.

You do not believe any of the women are victims of trafficking and know there will be very negative consequences for the women, some of whom are illegal migrants, if the police raid the brothel. Furthermore, if that happens, the organization will lose the confidence and trust of the women, and it is likely that the children will be taken from their mothers and placed into institutional care.

What do you say in the meeting and what would you recommend as an appropriate course of action?

EXAMPLE: An ethical dilemma resolved using The Four-Step Tool



© UNICEF, Ukraine, 2010, G.Pirozzi

IMAGINE... for a number of months, you have been working with a single mother who is known to use drugs. She is receiving HIV-related services from your outreach organization. She has a three-year-old daughter who lives with her. On a home visit you find needles on the floor of the apartment.

You are worried about the mother's safety, and worried about the child's safety as well. However, you do not want to report the situation, because you fear losing the client's trust—she is your client, after all. You also know that even if the child is removed from her parent, it will be difficult to find the child another home because the child is also HIV-positive.

This scenario is likely to provoke instant reactions, in part because parents who use drugs are highly stigmatised and we might make wrong assumptions about their ability to parent. Without adequate time to collect information and analyse the situation, many people would decide to remove the child from the setting where drugs are being used.

Keeping children safe from harm would be paramount, but jumping to conclusions based on bias and assumptions about safety could put the child at greater risk—for instance, if inadequate care for the child is available in an institutional setting. Furthermore, separation of the family, broken trust with the client, and legal action against the mother are also possible consequences. Such a decision could be unhelpful and harmful for both the child and the mother in the long run.

The removal of the child may be an option to consider amongst others, but it is important that before a decision is taken, there be a process that properly considers all of the information, potential actions and their likely impacts—a process that also helps us to question our own biases about parents who use drugs. This will ensure the best possible outcome in this situation.

Let us go through this scenario using the tool.

What is the situation or issue that you are having? Is it really a dilemma, or is it a common service delivery problem? If it is a dilemma, is it an *ethical* dilemma? (If it is not an ethical dilemma, then using this tool may not be as helpful to you. If you are unsure about the answer to these two questions, consult page 15 of the guidance.)
I have been supporting Maria with HIV services over a 6-month period. She is known to use drugs but has told me she is not currently using. She has a 3-year-old daughter who is also HIV positive and they live together. On a recent visit, I saw needles and syringes in the apartment left lying on the floor. I haven't mentioned what I saw to my client, but I am worried about the safety of her child. I know that the mother and child need our services and I don't want to jeopardise our relationship. *I am bound by my organisation to report my client if she is using drugs but I am worried about the consequences for her and her daughter. It is likely that her child will be removed if she is known to be using drugs and the child will most likely end up in an institution as no family will take her, as she is HIV positive.*

STEP 1: The 4-Box Method to Identifying the Facts & Assumptions

Adapted from Jonsen, Albert, Siegler, Mark and William J. Winslade (2002) Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine, McGraw-Hill Medical; 5th edition.

In each of the four boxes, there are a number of questions to prompt you to think about what important information you need in order to make a decision about the issue(s) that you are facing. Some of these questions may not be relevant to the issue(s) that you are trying to address, but they are designed to help identify what you know as facts, what you don't know, what are assumptions, and where you need to find out more information.

Remember, it is not necessary to answer all of the questions.

Health, Care, & Support Needs:	Client Preferences in this Situation:
For each client involved in the situation, think about the following questions, and answer as many as you think relevant: What do you think the client's needs are (e.g., health including treatment and medications; care; support; social needs, etc.), and are there other people whose needs should be considered? What about potential risks and harms? What other facts do you need? Be careful about unduly consulting with family or medical personnel who may, or may not have the best interest of the client in mind.	**For each client involved in the situation, think about the following questions, and answer as many as you think relevant:** Have you talked to the client about this situation? What are the client's expressed preferences? Is there any reason to believe that the client does not have the ability to make decisions? If yes, who is the substitute decision maker? If no, are client's wishes informed, understood, and voluntary? Is the client's right to choose being respected?
FACT: both mother and child are HIV positive and need to receive services, care and support.	*FACT: The client is committed to being a good mother and does not want to be separated from her daughter.*

~~FACT:~~ ASSUMPTION: It is likely my client will not go elsewhere to get services and without them she and her child will get sick.

FACT: If my client is using drugs again she will need additional support and services.

~~FACT:~~ ASSUMPTION: I worry that the child might be unsafe or in danger.

ASSUMPTION: I think that drug users can be good parents. Maybe my support could help Maria with her parenting.

~~FACT:~~ ASSUMPTION: If she is using drugs again, without adequate support, she may not be able to provide adequate care for her child.

~~FACT:~~ ASSUMPTION: The mother wants to stop using drugs.

Quality of Life:

For each client involved in the situation, think about the following questions, and answer as many as you think relevant:

How has the client described the current situation to you in the context of life generally? What would it mean to the client if you could meet the needs and preferences described? What difference would it make in the client's life? As a care worker, do you see it the same way? Consider emotions, feelings, values, biases and prior experiences of the people involved, including you. What are the consequences for you in supporting the client's preferences?

FACT: My client says she lives for her daughter and that without her there is no reason to carry on.

FACT: My client has expressed guilt and remorse about infecting her baby at birth.

QUESTION: Is the child in any real danger?

Contextual Issues:

For each client involved in the situation, think about the following questions, and answer as many as you think relevant:

What is the relevant social, economic, and/or institutional context? Are there organizational values to consider? What laws might have a negative impact on your client(s)? What laws might influence your response? Has anything changed recently that affects the situation? What other services are or could be involved? What plans have been put in place so far?

QUESTION: Is the drug using equipment hers, or could there have been someone else involved?

FACT: Sadly, there are very few alternative care options for an HIV positive child. She would be likely to be put in institutional care.

FACT: I would be fired if my organization knew that I knew about this and did not report her.

ASSUMPTION: If I report her, she is likely to reject me and refuse my services.

ASSUMPTION: Reporting could create fear from all of our clients. They wouldn't trust us any more.

STEP 2: Determine the Ethical Values & Principles in Conflict

Now that you've identified the facts, identify the ethical dilemma(s). Which ethical principles are in conflict?

Refer to the list in the left column and to the full Code of Ethics and Ethical Values and Principles on pages 16-18. It may help to explain the issue(s) first by using the facts from Step 1, and then to identify the ethical values and principles that correspond to the issue(s). State the ethical dilemma by explaining which ethical values and principles are in conflict – there may be more than two.

Circle the relevant ethical values & principles below:	Explain the Issue(s):
• *Dignity* • *Diversity* • *Advocacy* • *Security* • *Quality* • ***Accountability*** • *Privacy* • *Confidentiality* • ***Managing Conflicting Obligations*** • *Fair and Equitable Access* • ***Health and Wellbeing*** • *Informed Choice* • *Empowerment* • *Cooperation* • ***Family*** • ***Prioritizing children while supporting parents or caregivers in key popuplations***	• *My organisation requires me to report and I could lose my job if someone knew I knew and didn't report.* • *I believe my client should not be penalised just because she is using drugs—as long as she is caring for her daughter. I don't agree with my organisational policy.* • *If I report my client, it could lead to the mother withdrawing from services, and that could have consequences for her health and the health of her child.* • *Mother and child have the right to be a family.* • *If the child is in potential danger from the drug use of my client I would have to prioritise her safety*

Based on Steps 1 & 2, what is/are the ethical dilemma(s)?

I believe the mother is and can continue to be a good parent even as a drug user and that we should not assume otherwise. However, my organisational policy and the law say that she cannot be a good parent while using drugs, and that her daughter should be removed from her care.

If I report the situation to the authorities, the child could be taken away, but if I don't report it, I could lose my job.

STEP 3: Explore Options and Consider their Strengths and Weaknesses

Brainstorm all of the options that you can think of, even those that may not be ideal solutions. Brainstorm and discuss with peers as appropriate. Whenever possible, discuss the options with your client(s). Consider under what circumstance(s) you would not discuss the options with the client(s), and how you would justify that decision. Be creative and use your imagination. Consider a compromise. Think about the outcomes or consequences for each alternative. What is the good that might come of each option? What is the harm that might come of each option? Have the options you developed fit with the client(s)'s/family's statement of values and preferences, and the information that you obtained from your client(s)? Question whether the alternatives meet relevant policies, directives and regulations. Make sure that you weigh the strengths and weaknesses of all of the options before you make a decision. Consider which options do the most good or the least harm. Consider what ethical principles each option upholds or what ethical principles each option violates. Consider also how practical it would be to act on each option.

Option:	Strengths:	Weaknesses:
1) *Talk to my client about the drug use and unsafe disposal of equipment – find out more about how she is coping and set some timeframe for assessment of changes.*	• *Respects my client's right to be a parent regardless of drug use and keeps mother and child together while assessing the situation further.*	• *I may be risking the child's safety if there are bigger issues than I am aware of and my client's drug use is affecting my client's ability to care for and protect her child.*
2) *I report her to the organisation and let law and policy take their course.*	• *I protect myself from any disciplinary action and someone else more qualified can assess the risk and the action to be taken.*	• *I may be risking the child's safety if there are bigger issues than I am aware of and my client's drug use is affecting my client's ability to care for and protect her child.*
3) *I could ask the advice of a more senior colleague 'off the record'.*	• *It would allow me to get another perspective without escalating the situation and they may have dealt with something like this already.*	• *I risk my colleague reporting me and taking the situation out of my hands. I may lose respect from her if she sees my action as unprofessional.*

4) *I could do nothing. I have never seen needles lying around before. It may have been a one off.*	• *I don't have to confront my client and the issue may be resolved easily.*	• *I think I would feel uncomfortable that I have neglected to deal with the situation and if anything was to happen I would feel guilty.*

STEP 4: Choose an Option, Take Action, Evaluate and Debrief

Develop an Action Plan *(The actual plan should be documented)*

Given all the information that you have, choose the best option(s) available. Present alternatives to the client(s) and those involved. Re-examine the options if other factors come to light, if the situation changes, or if the client does not agree. Develop an action plan that includes what you are going to do and the steps that you are going to take. Determine when to evaluate the plan. Document and communicate the plan.

The plan is: *I will try option one. At least it gives my client the opportunity to discuss things with me. It may actually build trust if she knows that I am listening first.*

I will have to be clear about my responsibilities and agree with her how we can assess things going forward and at what point I would have to involve the organization.

Evaluate the Plan:

What was the outcome of the plan? How did the client(s) feel about how the issue was resolved? Is there need for further action?

My client was grateful I talked to her and didn't report her. She understood that I should have reported but respected her right to discuss it. She has promised me that it was a mistake and she has never left things lying around before and that she is feeling better. She said that she had a bad week but she is back on track.

She didn't like the idea that I needed to monitor things and that I might need to report in the future but I tried to explain the dilemma I am facing. I told her that I believe she is a good mother and that I want to support her and her daughter.

I don't know how to bring it up with my manager but this situation has made me feel strongly that as an organization we need to discuss our policies. It is not black and white. You can't say drug use = poor parenting. We need to have a better way to assess risk as outreach workers and also be able to discuss these dilemmas in our organization without risking our jobs.

Self-evaluate Your Decision and Debrief with Colleagues:

How do you feel about the decision and the outcome? What would you do differently next time? What would you do the same? What have you learned about yourself? What have you learned about this decision-making process? What can your organization learn from this situation? What changes can the organization make to better support people making similar decisions? What changes can the organization make to better address these types of situations?

I feel like I took a chance. It could have gone wrong, but luckily it didn't. I feel it was the right decision, especially after I had taken time to better assess the situation, but it was still not an easy decision.

I must admit that I did think 'what would happen if I got it wrong and something happened to her daughter?' but at the same time I knew I had to give the family a chance together.

As you can see from the example worked out above, even though we mean well, we can make decisions that have serious consequences if we do not stop to identify our bias, what the facts are, what assumptions we are making, and what questions we need answers to before we make decisions.

The situations we face in our work are not always easy, but completing this tool will help us to look at our options based on facts and ethical principles, and to think about what might happen if we make one decision instead of another.

By using this tool, we can make better decisions, work to reduce the stigma and discrimination that clients experience when receiving care, and improve the lives of children and families receiving care, treatment, and support.

Appendices:

IMAGINE... You are working with a young family: the parents, both teenagers, are HIV positive and have two children under the age of 2. The parents have both just tested positive for Hepatitis C. The organization that you work for has a policy of not providing Hepatitis C treatment for people who continue to inject drugs. You are the only person in the organization who knows that these parents are injecting drugs.

You know how important it is for these people to receive treatment. They have been working hard to look after their children, and in the past 6 months that you have been working with them, they have made huge progress. You know that for their health and future, they need to receive this treatment. You have tried to counsel the parents on stopping their use of injectable drugs, but they are choosing to continue. You do not know how to continue to support them and to respect the policy of your organization. You also worry that if they do not receive the Hepatitis C treatment, their health will decline and they will be at risk of losing their children.

What should you do? How will you decide?

Implementing this tool within your organization

© Eugenie Dolberg / IHAA

Orientation

This resource was written so that it can be used by an organization without extensive training. However, because ethics is a concept that is not easily understood by everyone, an orientation to the tool is strongly recommended. For that reason, there is an accompanying orientation slide package.

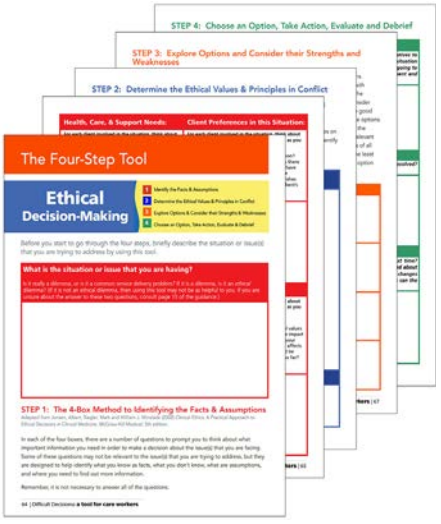
This orientation can take place in your staff team in four parts by:

1. Going through the orientation slide package, making sure that all users understand the meaning of an 'ethical dilemma' and how it is different from an ordinary dilemma and other types of service delivery problems;

2. Going through each section of the guidance to ensure there is a common understanding and comfort with using the tool;

3. Facilitating some discussion questions (see below); and

4. Having everyone work through the decision-making tool with a dilemma that you have recently encountered.



The following are some suggested discussion questions:

1. Does everyone understand how a common service delivery problem is different from a dilemma?

2. Does everyone understand how an *ethical* dilemma is different from other kinds of dilemmas?

3. Does everyone understand how ethical decision-making can be *influenced* by policies, human rights or the law, yet it is not the same thing as following a policy, upholding a right, or upholding the law?

4. Does everyone understand the purpose of the first step of the decision-making tool—the '4-Box Method'? Does everyone understand that it is not important that the information be placed in the correct box, but that it is important that the information be based on fact?

5. What are the limitations of this tool? Is everyone clear that this tool will not give them the answer to their dilemma?

6. Is everyone clear that this tool is not meant to be used in situations that are time-sensitive, and that there is a pocket guide at the end of the guidance that can be used for that purpose?

7. What are some examples of dilemmas where stigma or care worker bias might influence the care worker's decision? How might the tool help a care worker to identify and set aside his or her bias?

8. What is needed to support staff to use this tool consistently, and well?

Policy development

As you use the tool, care workers or managers may identify areas where a new policy might be needed, or where an old policy might need to be revised. But a policy cannot replace an ethical decision-making framework. A framework helps you make a decision, whereas a policy tells you how to act, or sets a minimum standard.

It is important to remember that policies might help us to avoid *some* ethical dilemmas, but many ethical dilemmas will still present themselves.

Debriefing cases

One of the most successful techniques to deal with moral distress and diminish moral residue is the process of debriefing. Debriefing is about coming together (as a group or just with another care worker) to talk about a traumatic event. Rather than keeping things bottled up, this allows us the opportunity to express our emotions and to reflect on what happened. Debriefing gives everyone the chance to let out their moral distress and to keep it from turning into moral residue.

Looking forward, debriefing also helps us learn more about ethics and improve how we deliver care in the future.

To do this properly, we need to create a safe, open, and supportive environment for everyone

© Jenny Matthews / Alliance

to express their feelings. Participation should be voluntary. It is also important to remember that this is not a 'blame' session, and should not be confused with an official investigation about what happened. Lastly, having someone experienced in leading a debriefing is helpful.

Regular case conferences

While debriefing specific cases in a team context should be voluntary, regular team case conferences can be used to discuss the issues that are raised by ethical dilemmas.

Responding to issues earlier

Instead of waiting for dilemmas to happen, and then debriefing, a staff team can take a situation that occurs frequently and go through it as a group, reflecting on the issues and thinking through the options. By using this approach, we can often apply the skills we learn to prevent future dilemmas.

Supporting care workers in other ways

There are other ways managers can support care workers who face tough decisions:

1. Recognizing moral distress and moral residue when they occur;
2. Supporting people on an individual basis when they need it;
3. Providing regular education on ethics topics; and
4. Having the leaders in the organization talk about the importance of ethics.

ADDITIONAL EXAMPLES:
of ethical dilemmas resolved using The Four-Step Tool

Example #1


© Alliance

Recall the following scenario:

You are a care worker supporting a single father and his fifteen-year-old daughter for the past three months. The father and daughter are both HIV-positive. The father has been coming to your organization regularly for counselling and HIV-related antiretroviral therapy (ART).

Recently, the father has missed his regular appointments at your organization, so you decide to visit the family at home to follow up with him and make sure that everything is all right.

When you go to the home, you find out that the father has been taking his daughter's medication. You try to counsel him about the importance of both of them taking the proper medication, but he dismisses your concerns. He asks you to leave and tells you that he knows best for his daughter, and he'll get her medication when she needs it.

What should you do?

Let's start by identifying the facts using the 4-Box Method, looking at what we know, what we don't know, what is a fact, what is an assumption, and what is an emotion…

STEP 1: The 4-Box Method to Identifying the Facts & Assumptions

Adapted from Jonsen, Albert, Siegler, Mark and William J. Winslade (2002) Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine, McGraw-Hill Medical; 5th edition.

In each of the four boxes, there are a number of questions to prompt you to think about what important information you need in order to make a decision about the issue(s) that you are facing. Some of these questions may not be relevant to the issue(s) that you are trying to address, but they are designed to help identify what you know as facts, what you don't know, what are assumptions, and where you need to find out more information.

Remember, it is not necessary to answer all of the questions.

Health, Care, & Support Needs:	Client Preferences in this Situation:
For each client involved in the situation, think about the following questions, and answer as many as you think relevant: What do you think the client's needs are (e.g., health including treatment and medications; care; support; social needs, etc.), and are there other people whose needs should be considered? What about potential risks and harms? What other facts do you need? Be careful about unduly consulting with family or medical personnel who may, or may not have the best interest of the client in mind.	**For each client involved in the situation, think about the following questions, and answer as many as you think relevant:** Have you talked to the client about this situation? What are the client's expressed preferences? Is there any reason to believe that the client does not have the ability to make decisions? If yes, who is the substitute decision maker? If no, are client's wishes informed, understood, and voluntary? Is the client's right to choose being respected?
FACT: My client and daughter need to take full dosage of their treatment. *FACT: There are health risks if they do not take the proper treatment.* *~~FACT:~~ ASSUMPTION: The family does not have enough money to access their treatment.* *QUESTION: Need to find out why the father has not come for his medications – Is it financial, is there stigma at the clinic, or is there some other reason?* *QUESTION: Are there other sources of support? Is the daughter getting any medication? How are the daughter's needs different from the father's?*	*Talked to the father. He asked me to leave before I could speak to the daughter. FACT: He wants to be left to make treatment decisions for his daughter without my support.* *FACT: I do not know the daughter's preferences yet.* *ASSUMPTION: Father is competent to make decisions. So is the daughter.* *QUESTION: Is the daughter deciding for herself to share her medications? Is her decision informed and voluntary?*

Quality of Life:	Contextual Issues:
For each client involved in the situation, think about the following questions, and answer as many as you think relevant: How has the client described the current situation to you in the context of life generally? What would it mean to the client if you could meet the needs and preferences described? What difference would it make in the client's life? As a care worker, do you see it the same way? Consider emotions, feelings, values, biases and prior experiences of the people involved, including you. What are the consequences for you in supporting the client's preferences?	**For each client involved in the situation, think about the following questions, and answer as many as you think relevant:** What is the relevant social, economic, and/or institutional context? Are there organizational values to consider? What laws might have a negative impact on your client(s)? What laws might influence your response? Has anything changed recently that affects the situation? What other services are or could be involved? What plans have been put in place so far?
FACT: From previous conversations with this family, I know that family is important to them. The daughter and father support each other in various ways. *FACT: The father has told me that it is important to him to be self-reliant.* *ASSUMPTION: The father seems satisfied with the current situation, but I'm uncomfortable about leaving things as they are.* *FACT: I'm worried that they will both become ill, and that I could have done more to help them.*	*FACT: Legally, the daughter cannot access medication without her father's consent.* *FACT: There is potential economic support to access treatment, if they need it.* *FACT: From previous conversations, I know that there are extended family members who help out from time to time.* *FACT: The family is involved in the local church.* *FACT: Legally, if I have evidence or even suspect that the daughter is having her medications withheld, I must report the family to child protection services.* *FACT: My organization's policy is that the client has the right to refuse service, but in this case, the daughter is also my client.* *FACT: I have 50 other clients and can't keep going back.*

STEP 2: Determine the Ethical Values & Principles in Conflict

Now that you've identified the facts, identify the ethical dilemma(s). Which ethical principles are in conflict?

Refer to the list in the left column and to the full Code of Ethics and Ethical Values and Principles on pages 16-18. It may help to explain the issue(s) first by using the facts from Step 1, and then to identify the ethical values and principles that correspond to the issue(s). State the ethical dilemma by explaining which ethical values and principles are in conflict – there may be more than two.

Circle the relevant ethical values & principles below:	Explain the Issue(s):
• ***Dignity***	• *Father wants to maintain dignity – my meddling in his decisions is compromising that.*
• *Diversity*	• *I feel a duty to advocate for the daughter, and for him – so that they both get the services they need.*
• ***Advocacy***	• *There's an issue of the quality of their treatment – not sure if the daughter is getting all the medications she needs. The father may not be either.*
• *Security*	• *I'm accountable to my organization (policy) and to the laws of my country (child protection), but my choices also have an impact on this family. I'm also accountable to my clients for my decisions.*
• ***Quality***	• *If I go to the extended family or to the church, I breach confidentiality.*
• ***Accountability***	• *Both the father and the daughter are my client. I have a duty to meet both of their needs, but I'm not sure how to fulfill this duty.*
• *Privacy*	• *Father says he doesn't need these services. I can't keep coming back. Other clients are also waiting in the queue for my services.*
• ***Confidentiality***	
• ***Managing Conflicting Obligations***	
• ***Fair and Equitable Access***	

• ***Health and Wellbeing***	• *Without full dosage, their health might decline.*
• ***Informed Choice***	• *Not sure yet if the daughter's decisions are informed or voluntary.*
• *Empowerment*	
• *Cooperation*	• *The father has a right to make his own decisions.*
• ***Family***	• *I want to support this family's self-reliance. This father believes he should be responsible for his daughter's health, but I am worried he is not fulfilling his responsibilities.*
• ***Prioritizing children while supporting parents or caregivers in key popuplations***	• *If it turns out the daughter's decisions aren't informed or voluntary, should I prioritize her needs over the needs of her father?*

Based on Steps 1 & 2, what is/are the ethical dilemma(s)?

If I push this father to let me talk to him and to take his medications properly, I'm not respecting what he wants or his self-reliance. But, if I don't push, I may not be doing my duty to ensure his health and well-being and his daughter's health and well-being.

(Other dilemmas?)

STEP 3: Explore Options and Consider their Strengths and Weaknesses

Brainstorm all of the options that you can think of, even those that may not be ideal solutions. Brainstorm and discuss with peers as appropriate. Whenever possible, discuss the options with your client(s). Consider under what circumstance(s) you would not discuss the options with the client(s), and how you would justify that decision. Be creative and use your imagination. Consider a compromise. Think about the outcomes or consequences for each alternative. What is the good that might come of each option? What is the harm that might come of each option? Have the options you developed fit with the client(s)'s/family's statement of values and preferences, and the information that you obtained from your client(s)? Question whether the alternatives meet relevant policies, directives and regulations. Make sure that you weigh the strengths and weaknesses of all of the options before you make a decision. Consider which options do the most good or the least harm. Consider what ethical principles each option upholds or what ethical principles each option violates. Consider also how practical it would be to act on each option.

Option:	Strengths:	Weaknesses:
1) Go back, try one more time to find out if the daughter's decision is voluntary and informed. • If the decisions are informed and voluntary, leave and do nothing (except document).	• I fulfilled my obligations.	• If the daughter is deciding to share her medications, and her decision is voluntary and informed, their physical health will still suffer from poor adherence to treatment.
• If the decisions are not informed and voluntary, try one more time to find out the problem and convince the father to accept support in order that they both get medications.	• The situation is sorted out.	• The father may lose his trust in me and may feel like he is losing his self-reliance.
• If the father still refuses support, then report to child protection.	• The daughter may get her medications.	• The father may lose trust in me and lose self-reliance. He may feel betrayed. • Child protection may do nothing, the trust is broken, and yet the treatment issue is not resolved. • The family could be split apart. • They may both lose faith in our services and stop accessing our services.
2) Don't go back. Don't report the family. Hope there is no child neglect.	• Respects the father's preferences.	• I won't find out the daughter's preferences. The treatment issues are not resolved. • I will feel that I've let the family down, or that I have not fulfilled my duties.

3) *Don't go back. Report family to child protection.*	• *Technically, I fulfill my obligations under the law.*	• *The father will lose trust in me and feel betrayed.* • *Child protection may do nothing, the trust is broken, and yet the treatment issue is not resolved. The family could be split apart.* • *They may both lose faith in our services and stop accessing our services.* • *Client's confidentiality is breached. The family will lose trust in me.* • *Devastating consequences could ensue for the father and daughter, for their family, and for the community.* • *I might lose my reputation and then others might lose trust in our services.*
4) *Go to visit friends or extended family and see if they can help.*	• *The treatment issues may be solved if they convince the family to access full treatment.*	• *Client's confidentiality is breached. The family will lose trust in me.* • *Devastating consequences could ensue for the father and daughter, for their family, and for the community.* • *I might lose my reputation and then others might lose trust in our services.*
5) *Go to the local church –see if there can be any outreach to the family.*	• *The treatment issues may be solved if they convince the family to access full treatment.*	• *Client's confidentiality is breached. The family will lose trust in me.*

		• Devastating consequences could ensue for the father and daughter, for their family, and for the community. • I might lose my reputation and then others might lose trust in our services.
6) Keep engaging with the family. Don't give up after two tries.	• Could strengthen the relationship. • Could solve the treatment problem eventually.	• Could alienate the family completely. They may withdraw from services entirely. • You might not be able to see other clients who are waiting for and interested in your services. • I might lose my reputation and then others might lose trust in our services.
7) Other options?		

STEP 4: Choose an Option, Take Action, Evaluate and Debrief

Develop an Action Plan *(The actual plan should be documented)*

Given all the information that you have, choose the best option(s) available. Present alternatives to the client(s) and those involved. Re-examine the options if other factors come to light, if the situation changes, or if the client does not agree. Develop an action plan that includes what you are going to do and the steps that you are going to take. Determine when to evaluate the plan. Document and communicate the plan.

The plan is: Option 6: Keep engaging with the family. Don't give up after two tries.

Evaluate the Plan:

What was the outcome of the plan? How did the client(s) feel about how the issue was resolved? Is there need for further action?

I kept trying to talk to the daughter and father. The father eventually let me in. I found out that the daughter's preferences were not being respected, but I also discovered the father wasn't coming for his medications because on previous visits to my organization he was badly

treated by one of the doctors. I assisted him in making the next appointment, advocated for him to change doctors, and raised the issue of maltreatment with my colleagues. We are planning a discussion about this, and I will propose training for the health care providers. The daughter and father are receiving and taking their medications. I'm now making regular visits and the trust between me and the family has been strengthened.

Self-evaluate Your Decision and Debrief with Colleagues:

How do you feel about the decision and the outcome? What would you do differently next time? What would you do the same? What have you learned about yourself? What have you learned about this decision-making process? What can your organization learn from this situation? What changes can the organization make to better support people making similar decisions? What changes can the organization make to better address these types of situations?

I feel glad that I kept going back to try to talk to family, even though there were risks. I'm glad that I was able to resolve this without calling child protection. Filling in the tool helped me realize there were extreme consequences if I had made another decision. My organization has learned that by using the tool, we avoided a situation where we would have lost credibility in the community. We learned that quick decisions made without thinking about all of the consequences can have a negative impact on the family we were trying to help.

Example #2

© R.Srinivas Photovoice/ Alliance

Recall the following scenario:

Your client who is HIV-positive and is not regularly taking his HIV medications tells you he is getting married. He has been feeling much pressure from his family to find a bride. The wedding is happening in two months and his bride-to-be is a woman that you know well in social circles.

Your client tells you they have not had sex yet, but that after the wedding, he and his bride plan to have a baby. He asks that you not tell his fiancée that he is HIV-positive, or that he has occasionally had sex with men in the past. You worry that his viral load will make him infectious, that his bride will become infected with HIV, and that if she doesn't know her own HIV status, she may pass on HIV to their baby.

You repeatedly try to counsel him to tell his fiancée the truth, but he refuses, and will not consider breaking off the engagement. You will continue to counsel him to be strict about taking his medications, but his past history suggests he cannot easily stick to the regimen.

What should you do?

STEP 1: The 4-Box Method to Identifying the Facts & Assumptions

Adapted from Jonsen, Albert, Siegler, Mark and William J. Winslade (2002) Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine, McGraw-Hill Medical; 5th edition.

In each of the boxes, there are a number of questions to prompt you to think about what important information you need in order to make a decision about the issue(s) that you are facing. Some of these questions may not be relevant to the issue(s) that you are trying to address, but they are designed to help identify what you know as facts, what you don't know, what are assumptions, and where you need to find out more information.

Remember, it is not necessary to answer all of the questions.

Health, Care, & Support Needs:	**Client Preferences in this Situation:**
For each client involved in the situation, think about the following questions, and answer as many as you think relevant: What do you think the client's needs are (e.g., health including treatment and medications; care; support; social needs, etc.), and are there other people whose needs should be considered? What about potential risks and harms? What other facts do you need? Be careful about unduly consulting with family or medical personnel who may, or may not have the best interest of the client in mind.	**For each client involved in the situation, think about the following questions, and answer as many as you think relevant:** Have you talked to the client about this situation? What are the client's expressed preferences? Is there any reason to believe that the client does not have the ability to make decisions? If yes, who is the substitute decision maker? If no, are client's wishes informed, understood, and voluntary? Is the client's right to choose being respected?
FACT: My client's family is pressing him to get married. *FACT: If the client doesn't adhere to his treatment, his viral load will be so high that transmission of HIV to his bride is likely. Since they are trying to have a baby, they will not be using condoms.* *~~FACT:~~ ASSUMPTION: If they have a baby, HIV will be transmitted to the child (Question: find out how routine the hospital protocols are around testing pregnant women in order to prevent mother to child transmission of HIV).* *QUESTION: Is there anything I could try that would help him adhere to medications?*	*FACT: Client doesn't feel able to tell his bride the truth about being HIV positive.* *~~FACT:~~ ASSUMPTION: His bride doesn't know the truth. Question: Ask client, is it possible his bride knows about his HIV status or about his having sex with men?* *QUESTION: Does the client use protection when he has sex outside of his marriage?* *~~FACT:~~ ASSUMPTION: He may continue to have sex with men outside of his marriage, which could put his wife at further risk of sexually transmitted infections if he has unsafe sex.* *QUESTION: Do I care that the client has sex with other men? Do I care that the client has sex outside of his marriage? What are my feelings about this?*

Quality of Life:	Contextual Issues:
For each client involved in the situation, think about the following questions, and answer as many as you think relevant: How has the client described the current situation to you in the context of life generally? What would it mean to the client if you could meet the needs and preferences described? What difference would it make in the client's life? As a care worker, do you see it the same way? Consider emotions, feelings, values, biases and prior experiences of the people involved, including you. What are the consequences for you in supporting the client's preferences?	**For each client involved in the situation, think about the following questions, and answer as many as you think relevant:** What is the relevant social, economic, and/or institutional context? Are there organizational values to consider? What laws might have a negative impact on your client(s)? What laws might influence your response? Has anything changed recently that affects the situation? What other services are or could be involved? What plans have been put in place so far?
FACT: Would my client want to get married if his family were not pressing him to do so? He says it's important that he live a life that conforms to his family's expectations – and he wants children. He says he loves the woman he's marrying. *FACT: The client's quality of life depends on my keeping his information confidential. If I disclose his information to his bride, I could lose my job, and my credibility as a care worker.* *ASSUMPTION: His bride does not appear to have a choice in this situation and her quality of life will be jeopardized if she becomes HIV-infected.* *QUESTION: what is my duty here? Is his bride in imminent danger?*	*FACT: Client is pressed by his family to get married and seems unable to resist the pressure.* *~~FACT:~~ ASSUMPTION: We are the only AIDS service organization in our community. If I breach confidentiality, the client may never trust the organization again, and his own health could suffer.*

STEP 2: Determine the Ethical Values & Principles in Conflict

Now that you've identified the facts, identify the ethical dilemma(s). Which ethical principles are in conflict?

Refer to the list in the left column and to the full Code of Ethics and Ethical Values and Principles on pages 16-18. It may help to explain the issue(s) first by using the facts from Step 1, and then to identify the ethical values and principles that correspond to the issue(s). State the ethical dilemma by explaining which ethical values and principles are in conflict – there may be more than two.

Circle the relevant ethical values & principles below:	Explain the Issue(s):
• Dignity • Diversity • Advocacy • Security • Quality • Accountability • **Privacy** • **Confidentiality** • **Managing Conflicting Obligations** • Fair and Equitable Access • **Health and Wellbeing** • **Informed Choice** • Empowerment • Cooperation • **Family** • Prioritizing children while supporting parents or caregivers in key populations	• The client has a right to a private life. If I disclose information to his bride, his privacy is breached. • I have an ethical and an organizational duty to keep my client's information confidential – and I have made that promise to him. • I have an organizational duty to my client, but I believe I have an ethical duty to warn his wife that she may be at imminent risk of infection from a currently incurable virus • If I disclose my client's HIV status, his life situation—and therefore his mental health—could be seriously harmed. However, the health and wellbeing of his fiancée is at risk, and so is, potentially, the health of a child. • The client's wife is not necessarily making an informed choice about whom she is marrying, about whether or not she should be using protection when they have sex, or about alternative methods to conceive a child. • I want to support the right of people living with HIV to be parents.

Based on Steps 1 & 2, what is/are the ethical dilemma(s)?

The ethical dilemma is: Do I disclose the client's confidential information in order to protect a woman from HIV infection, thereby breaching the client's trust and possibly jeopardizing the possibility of his receiving good HIV care, or do I keep the information confidential and give up any responsibility to warn the client's bride?

STEP 3: Explore Options and Consider their Strengths and Weaknesses

Brainstorm all of the options that you can think of, even those that may not be ideal solutions. Brainstorm and discuss with peers as appropriate. Whenever possible, discuss the options with your client(s). Consider under what circumstance(s) you would not discuss the options with the client(s), and how you would justify that decision. Be creative and use your imagination. Consider a compromise. Think about the outcomes or consequences for each alternative. What is the good that might come of each option? What is the harm that might come of each option? Have the options you developed fit with the client(s)'s/family's statement of values and preferences, and the information that you obtained from your client(s)? Question whether the alternatives meet relevant policies, directives and regulations. Make sure that you weigh the strengths and weaknesses of all of the options before you make a decision. Consider which options do the most good or the least harm. Consider what ethical principles each option upholds or what ethical principles each option violates. Consider also how practical it would be to act on each option.

Option:	Strengths:	Weaknesses:
1) *Warn the client's bride that he is HIV positive and occasionally has sex with men.* • *Tell the client I have an ethical duty to warn his bride that he is HIV positive and has sex with men, and that I will do so in a week's time unless he tells her himself. Tell him I will support him to tell her.*	• *I fulfil my duty to warn a woman that she may be at risk of HIV infection and sexually transmitted infections, and this could result in also preventing a child from being born with HIV.* • *By warning my client first, I give him the choice to have more control of the situation.*	• *I may lose the trust of my client. He may never return for service. He is not treatment adherent and I worry this will put his own health more at risk.* • *I am not sure that the client will continue to have sex with men after he is married, or even if he has sex outside his marriage, that he will do so without using protection. If that is the case, warning against infidelity is not really my place.* • *The only reason to mention the fact that he has had sex with men, is that I am assuming that his past behaviour with*

		men was unsafe, and that it is a predictor of future unsafe sex during his marriage. Taking action based on this assumption may be acting based on my own bias about men who have sex with men. • If she is angry, she could disclose this information more widely causing terrible consequences for my client. • I could lose my job.
2) Warn the client's bride that he is HIV positive • Tell the client I have an ethical duty to warn his bride that he is HIV positive, and that I will do so in a week's time unless he tells her himself. Tell him I will support him to tell her. Tell him I will not disclose the fact that he has in the past had sex with men.	• I fulfil my duty to warn a woman that she may be at risk of HIV infection, and this could result in also preventing a child from being born with HIV. • I warn the woman of the risk of contracting a sexually-transmitted infection, but I don't expose the client to the social stigma associated with having sex with men. • By warning him first, I give him the choice to have more control of the situation.	• I may lose the trust of my client. He may never return for service. He is not treatment adherent and I worry this will put his own health more at risk. • If she is angry, she could disclose this information to others causing terrible consequences for my client—though perhaps not as serious consequences as if she disclosed that he also had sex with men. • I could lose my job.
3) Do nothing.	• Respecting the client's wishes fulfills my ethical duty to protect his confidentiality and conforms to my organization's policies.	• A woman could be infected with HIV, and possibly also with sexually transmitted infections (although I am not sure of that), when my actions

	• I will keep my job.	could prevent it. • A child could possibly be born with HIV because I did nothing.
4) Tell him you will have to warn his bride that he is HIV positive (but not that he has had sex with men) unless together, you and he can find a way to support him to be adherent to his HIV medication and therefore reduce his viral load to undetectable so he is no longer significantly infectious.	• Gives the client more control of the situation, warning him of possible consequences, while supporting him to take care of his own health.	• The wife may still be at a small risk. I may never know for sure if he is adherent to his medication. • If the strategy fails and I know that he is not being adherent, then I will have to try another option anyway, and by then it may be too late.
5) Other options?		

STEP 4: Choose an Option, Take Action, Evaluate and Debrief

Develop an Action Plan *(The actual plan should be documented)*

Given all the information that you have, choose the best option(s) available. Present alternatives to the client(s) and those involved. Re-examine the options if other factors come to light, if the situation changes, or if the client does not agree. Develop an action plan that includes what you are going to do and the steps that you are going to take. Determine when to evaluate the plan. Document and communicate the plan.

The plan is: Option 4, then if that doesn't work, Option 2: I will try very hard to set up a treatment adherence plan with the client so that I am not faced with the choice of breaching this confidentiality. However, if within one month, I am still not certain that he is adhering to his medications, I will warn him that within one week, I will tell his bride that he is HIV positive, unless he discloses the information himself. I will tell him I will support him to make the disclosure if he wishes. I will promise him that I will not disclose that he has had sex with men, as I do not believe it is relevant to the situation, and I have no proof that his past behaviour is a predictor of his having unsafe sex with other men (or women) during his marriage.

Evaluate the Plan:

What was the outcome of the plan? How did the client(s) feel about how the issue was resolved? Is there need for further action?

The client was angry with me—and nearly left the organization over his feeling of betrayal.

The client reported my actions to my supervisor and I got a letter of reprimand, but I kept my job. The client and I worked together to find solutions to adhering to his medication, and he kept to his treatment plan. I decided to do nothing. After several months and many discussions, I feel that trust is slowly rebuilding. This has led to more honest discussions about my duty and his rights.

My client pointed me to UNAIDS guidelines that require me to make sure a person has legal protection or support if ever I feel I must disclose someone's HIV status in order to protect someone else. That is something that I did not think of in my decision-making process.

In our organization, this has led to more discussions about the limits of confidentiality, and our director is considering a review of our policy on confidentiality, as well as our intake procedures during which we explain this policy to new clients.

Self-evaluate Your Decision and Debrief with Colleagues:

How do you feel about the decision and the outcome? What would you do differently next time? What would you do the same? What have you learned about yourself? What have you learned about this decision-making process? What can your organization learn from this situation? What changes can the organization make to better support people making similar decisions? What changes can the organization make to better address these types of situations?

I still worry that my client could stop taking his medications, and that my actions could result in a woman, and possibly a child, becoming HIV-positive. I am also concerned that my relationship with my client has suffered and cannot be repaired. I feel guilty, but I also know that my choice caused the least harm given the circumstances.

Suggested Additional Readings and Resources

- Engaging with Men Who Have Sex With Men in the Clinical Setting, from http://www.msmgf.org/files/msmgf/Publications/MSMGF_Healthcare_Primer.pdf
- GNP+, UNAIDS (2011). Positive Health, Dignity and Prevention: Policy Framework, from http://www.gnpplus.net/images/stories/PHDP/GNP_PHDP_ENG_V4ia_2.pdf
- GIPA Good Practice Guide, from http://www.gnpplus.net/images/stories/Empowerment/GRC/GIPA_Good_Practice_Guide.pdf
- Integrating Stigma Reduction into HIV Programming: Lessons from the Africa Regional Stigma Training Programme, from http://www.aidsalliance.org/publicationsdetails.aspx?id=90523
- International HIV/AIDS Alliance, 100 ways to energise groups, Games to use in workshops, meetings and the community, from http://www.aidsalliance.org/includes/Publication/ene0502_Energiser_guide_eng.pdf
- Macer, Darryl RJ (2008) Moral Games for Teaching Bioethics, UNESCO Chair in Bioethics.
- Reaching MSM in the Global HIV and AIDS Epidemic, from http://www.msmgf.org/files/msmgf/Advocacy/MSMGF_ReachingMSMlowres.pdf
- The Robert Carr Doctrine – Principles for a meaningful response to HIV among the World's Key Affected Populations, http://www.msmgf.org/files/msmgf/documents/RobertCarrDoctrine.pdf
- Social Discrimination Against Men Who Have Sex With Men - Implications for HIV Policy and Programs from http://www.msmgf.org/files/msmgf/Advocacy/Policy_Briefs/Stigma_EN_hi.pdf
- Thogomelo Psychosocial Support for Caregivers Training Learning Manual, from http://issuu.com/jacanamedia/docs/thogomelo_pss_learners_manual
- Understanding and challenging stigma- Introduction, from http://www.aidsalliance.org/publicationsdetails.aspx?id=255

Glossary of Terms Commonly Used

TERMS	DEFINITIONS
'Affected by HIV' versus 'Infected with HIV'	For the purposes of this guidance, people who are described as 'affected by HIV' include both people who are not infected with the virus but whose lives are affected, and those who are infected with the virus. In this document people who are infected with the virus are referred to as 'people living with HIV' (see definition below).
Beliefs	A person's opinions or convictions
Bias and prejudice	Bias can come in many forms and is similar to prejudice—the feeling or sentiment that comes from judging a person or a group of people based on false information, missing information or no information at all ('pre-judging'). In this guidance it refers to a negative and harmful perspective about a person or a group of people who belong to one of the 'key population' groups (see definition below). When people have bias or prejudice, it refers to a feeling or sentiment, unlike discrimination, which is the action that results from bias (see definition below).
Burnout	A situation when people are so burdened or overworked that they feel they cannot continue. If a care worker does not quit work, those feelings of burnout can lead to poor care and support of clients, and worsening mental and physical health for the care worker *"Moral distress"* and *"moral residue"* can lead to burnout.
Child	UNICEF defines a child as being under eighteen years of age. In this guidance, if no qualification is given, it means anyone under 18 years of age. If we refer to 'young child' it means twelve years and under, to distinguish those children from adolescents who are over twelve and under eighteen years.
Child safeguarding	The concept of 'child safeguarding' or keeping children safe is an organizational responsibility to prevent, protect, and act in cases of suspicion; and always to put the child at the centre of the response. There must be a strong focus on making sure that organizational actions do not place children at further risk—in other words, acting in the best interest of the child. Not acting is not an option, but child removal is not necessarily the solution. It is important to distinguish between two different categories of child safeguarding: The first is when children are in need of protection because of circumstances such as emergencies, war, situations where children are displaced and separated from families, or where the family is under extreme stress (for instance economic stress, or stress from having to split up or from being dispersed).

	The second category arises when there is suspicion of specific incidents of maltreatment (abuse) that may be physical, sexual, and emotional, or caused through neglect.
Code of Conduct/Ethics	A set of rules or values that guide one on what should be done.
Confidentiality	A duty, based on an agreement, to protect private information. The difference between privacy and confidentiality is that privacy is about people's interest in controlling the access of others to themselves. Confidentiality, on the other hand, refers to the agreement between the person seeking information and a participant in how information or data will be managed and used.
Conflict of Interest	A clash between one's own personal or professional interests and the duties we owe to others. In good policies about conflict of interest, individuals and organizations are asked to consider whether the conflict is potential, perceived or actual.
Consent	To give permission for something to happen. Consent may be informed, or uninformed. See also 'Informed'.
Debriefing	Coming together (as a group or just with another care worker) to talk about a traumatic event with the aim of preventing moral distress from turning into moral residue.
Dignity	A person's right to be treated as a human being worthy of respect.
Dilemma	A dilemma is a situation in which a difficult choice has to be made between two or more options, especially between what appear, at first, to be equally *undesirable* options. It is important to understand that not all dilemmas are ethical dilemmas. That is to say that some dilemmas do not involve a conflict between ethical values or principles. An example of an ordinary dilemma, one that does not involve a conflict between ethical values and principles is deciding between a) riding a bicycle to work on a rainy day and getting there on time, but arriving wet, and b) taking public transportation to work and arriving dry, but arriving late. An ethical dilemma is a situation where different values, beliefs, responsibilities, or concerns pull us in different directions, and we are trying to make a decision that does the most good or causes the least harm. There are many examples of ethical dilemmas in this guidance.
Discrimination	(See *Stigma, to stigmatise, discrimination*).
Diversity	Respecting differences between people.
Ethical dilemma	A situation where different values, beliefs, responsibilities, or concerns pull us in different directions, and we are trying to make a decision that does the most good or causes the least harm.

	What makes an ethical dilemma different from an ordinary dilemma is that ethical values and principles are concerned.
Ethics	How we understand what is 'right' or 'wrong', 'good' or 'bad', and 'just' or 'unjust', regardless of where we are from, where we live, our religious beliefs, gender identity, sexual orientation, culture, policies, or the law.
Ethics framework	A guide designed to help us sort through conflicting values and responsibilities when ethics problems arise.
Family	In this guidance, family refers to any unit of two or more people bound together by a close bond who self-identify as a family, and often—but not always—includes children. It does not imply co-habitation. Family can include people connected by biology, adoption, kin, or unions based on love, affection or responsibility. Like all human beings, all members of key populations have families.
Gay man/ Gay men	A man who is physically and emotionally attracted to other men and who identifies as such, at least personally if not to friends, family, and others. This term is used purposefully instead of the more stigmatizing clinical or medical term 'homosexual'.
HIV and AIDS	HIV means 'human immunodeficiency virus' which weakens the body's immune system, whereas AIDS ('acquired immunodeficiency syndrome') is a clinical syndrome of opportunistic infections and diseases that can develop as immuno-suppression deepens.
Informed	Being given enough details about something such that one has no further questions. This concept is the subject of great debate in the caring professions: how many details are 'enough' is subjective, as is how often one should be reminded of those details. Many argue that it is difficult even to know what questions to ask in order to become informed.
Justification	The reasons we give to support what we believe.
Key population	For the purpose of this guidance, this term refers to the following groups of people; people living with HIV, people who use drugs, sex workers, transgender people, gay men, and other men who have sex with men. In different settings, other groups may be included in the term 'key population'.
Marginalization	Discrimination that pushes a group into a position on the fringes of society. Often this results in being cut off from key positions of power or positions of broad influence.
Man who has sex with men/ Men who have sex with men (MSM)	Men who have sex with men' and the corresponding acronym 'MSM' refer to all men who engage in same-sex sexual behaviour. This behaviour can take place in many different settings and contexts, and can come from a variety of motivations. MSM may differ widely in the way they self-identify—in terms of their sexuality, in terms of their gender identity or expression, and/or in terms of their connection to particular communities. For instance, while a proportion of MSM may choose

	to identify as gay or bisexual, some better relate to an identity that is unique to their own culture. Still others remain identified as heterosexual, while continuing to engage in same-sex behaviours. (Adapted from MSMGF Strategic Plan 2012-2015 and MSMGF Healthcare Primer for Physicians, Nurses and Other Healthcare Providers).
Moral Distress	The unease we feel from not being able to do what we think is right.
Moral Residue	The burden we carry from not making what we thought was the moral choice, or from having to act when we know that the option we choose will cause significant harm.
Morals	Our culture's beliefs about right and wrong. Because cultures have different beliefs, and because cultures are made up of many sub-cultures, different groups may have different morals.
A person living with HIV (PLHIV)	A person living with the human immunodeficiency virus. Many other terms have been used over the years, but the words 'person' and 'living' in this term are purposefully used to underline the fact that people living with HIV have and enjoy full lives worthy of the same respect, dignity and human rights as everyone else.
People who use drugs	People who use currently illicit substances. These people may be occasional or regular users of drugs. Many other terms have been used over the years, but this term purposefully starts with the word 'people' and does not contain the words 'addict' or 'addiction'.
People who inject drugs	People who currently use their drugs by injection. They may be occasional or regular users of injectable drugs. People who inject drugs potentially face greater harms due to their increased vulnerability to HIV and hepatitis B and C transmission.
Power	Our ability to act and influence the world around us.
Principle	A basic belief or rule. In the case of ethics, it is a belief or rule about what is ethical. The principles of this guidance are spelled out in the Code of Ethical Values and Principles.
Privacy	The ability of an individual or group to hide themselves or information about themselves, and/or to reveal those things as they wish. The difference between privacy and confidentiality is that privacy is about people's interest in controlling other people's access to themselves. Confidentiality, on the other hand, refers to the agreement between the person seeking information and a participant in how information or data will be managed and used.
Problem (in the delivery of care, treatment or support)	Any situation, including an ordinary dilemma or an ethical dilemma, which requires a solution. All dilemmas are problems, but not all problems are dilemmas. What separates a dilemma from a common service delivery problem is that with a dilemma there are two or more undesirable options.

Quality of Life	A person's own view about how well his/her own life is going.
Relationship	The connections and bonds that people share.
Risk	The chance of being injured or harmed.
Safety	Being protected from injury or harm.
Sex work	The exchange of money or goods in exchange for the sexual services of adults. Sex work is an income-generating activity that is a legitimate form of labour, and sex workers should enjoy rights, be protected from harm and be accorded the dignity enjoyed by other workers.
Sex workers	Female, male and transgender adults who receive money or goods in exchange for sexual services, either regularly or occasionally. The term sex worker refers only to adults. Young people under the age of 18 selling sex should not be included in this definition, as international human rights treaties explicitly define them as sexually exploited and outside of any child labour framework.
Stereotype	A generalization or belief about a group of people that is widely held, oversimplified, and often false.
Stigma, to stigmatize, discrimination	Stigma is when a person or group of people is thought to have less worth, or when a mark of disgrace is associated with a particular circumstance, quality or person. Stigma—like bias or prejudice—is an attitude. To stigmatize someone is to describe or regard as worthy of disgrace or great disapproval, and in this way it is can be either an action or an attitude. Discrimination is the act of treating someone differently in a way that is unjust or unfair—mostly because of stigma, bias or prejudice. Together the impact of stigma, stigmatization and discrimination can be devastating to individuals and groups who are targeted
Transgender person	A person whose gender identity or gender expression differs from the sex that was assigned to them at birth.
Trust	Being able to rely on another person when there is a risk of betrayal.
Value	Something we believe to be important.
Voluntary	Doing something of your own free will.
Vulnerable	Being in a position where one can be harmed.

Acknowledgements

The principal authors -- Kimberley Ibarra, John Miller, & Frank Wagner, wish to acknowledge that the tool at the centre of this guidance was adapted from the Community Ethics Network's Community Ethics Toolkit: *Ethical Decision Making in the Community Health and Support Sector* (Toronto Central Community Care Access Centre, July 2008).

We also wish to acknowledge the contributions of:

- Michelle Thorpe for her design work,
- Hong Lee and Dr. Mikey Dunn (a member of the working group) to the preamble and the code of Ethics;
- Sally Qi to the writing of the scripts for the video components, and to the survey results report, from which some of the language in this document has been pulled;
- Kate Iorpenda and Ruth Morgan-Thomas (members of the working group) and Sally Qi to the writing/ adaptation of case scenario from real-life situations faced by colleagues or shared with us during our research;
- DJ Glissen for his videography; and
- the other working group members—Jude Byrne, Mingaudas Busevičius, Georgina Caswell, Harriet Chiomba, Anjali Gopalan, JoAnne Keatley, Tudor Kovacs, Ed Ngoksin, Maria Phelan, Linnea Renton, & Mohan Sundararaj—for their feedback and for the critical role they played in conceptualizing of this project and shaping the content of this guidance.

The following individuals have given their time and energy to either the planning, drafting, reviewing or evaluating of this guidance or related materials, and for that we are immensely grateful:

Terhi Aaltonen, Larisa Abrickaja, George Ayala, Ameck Ayong, Damon Barrett, Jennie Butler, the late Robert Carr, Alison Crocket, Muhammad Daruz; Vivek Diwan, Irena Ermolaeva, Matron Fadzilah, Fatiiah from Rumah Solehah, Yong Feng, Nina Ferencic, Lucy Hillier, Robin Jackson, Jamaliah from the PT Foundation; Elisha Kor (Rina); Patricia Lim Ah Ken, Sian Long, Christoforos Mallouris, Daniella Mark, Scott McGill, Mickey Meiji, Duncan Moeketse, Norlela Mokthar, Freddy Molano, Samuel Obara, Miriam Sabin, Loreta Stonienė, Manohara Subramaniam, Jim Watson, Rachel Yates and Iryna Zharuk.

The authors are grateful to the following organizations for supporting, reviewing or pilot testing early versions of this guidance:

The Coalition for Children Affected by AIDS; Alliance Ukraine; Center for Excellence for Transgender Health, UCLA; Community Healthcare Network, New York; Demetra—Association of HIV Affected Women and Their Family (Lithuania); The Egmont Trust; The Ethox Centre at University of Oxford; Global Forum of MSM & HIV (MSMGF); Global Network of People Living with HIV (GNP+); Global Network of Sex Work Projects (NSWP); Harm Reduction International; International HIV/AIDS Alliance; International Network of People who Use Drugs; Malawian Network of People Living with HIV (MANET+); NAZ Care Home (India); The Malaysian AIDS Council; Muslim Women and Children's Shelter – Kuala Lumpur; PSI Romania; PT Foundation—Positive Living Program – Kuala Lumpur; Public Foundation Asteria – Kyrgyzstan; The Teresa Group (Canada); The Toronto Central Community Care Access Centre; UNAIDS; UNICEF; University of Toronto Joint Centre for Bioethics; Women and Health Association Kuala Lumpur

The following individuals have lent us their faces and voices for video clips to be used in the promotion of this guidance, and for that we are immensely grateful:

Amitava Sarkar, Arnold Macauley, Cecila Chung, Cyriaque Yapo Ako, C.K., H.W., Eddie Banda, Faraz Siddiqui, Ibrahima Ba, Jose Manuel Pinto dos Reis da Quinta, Mariam Afridi, Maureen Owino, Mluleki Zazini, Rodrigo Pascal, Roman Yorick, Romyen Tangsubutra, Thembi Nkambule, & Timothy Ng.Nelson Mandela Children's Fund; STOP AIDS NOW!; and The Egmont Trust

The following funders' contributions have made this guidance possible:

Bernard van Leer Foundation; Children Affected by AIDS Foundation; Conrad N. Hilton Foundation; Diana Princess of Wales Memorial Fund; Elizabeth Glaser Pediatric AIDS Foundation; Firelight Foundation; Global Fund for Children; HelpAge International (for funds from the Sweden and the Norwegian Agency for Development Cooperation); Nelson Mandela Children's Fund; STOP AIDS NOW!; and The Egmont Trust

The following organizations will be acting as evaluation sites for an external evaluation of this guidance, and for that, the authors are very grateful:

Network of People Living with HIV in Kenya (NEPHAK); Soins Infirmiers et Développement Communautaire (SIDC) Lebanon; Victorian AIDS Council/ Gay Men's Health Centre, Australia.

Bibliography

Anstey, K. W., & Wagner, F. (2008). Community healthcare ethics. In P. A. Singer, & A. M. Viens, The Cambridge Textbook of Bioethics (pp. 299-305). New York: Cambridge University Press.

Aulisio, M. P., May, T., & Aulisio, M. S. (1998). Vulnerabilities of clients and caregivers in the homecare setting. In Generations (pp. 58-63).

Ayala, G., Do, T., Semugoma, P., & Sundararaj, M., (2011) Engaging with Men Who Have Sex with Men in the Clinical Setting: A Primer for Physicians, Nurses, and Other Health Care Providers. Global Forum on MSM & HIV (MSMGF) from http://www.msmgf.org/files/msmgf/Publications/MSMGF_Healthcare_Primer.pdf

Baylis, F., Kenny, N., & Sherwin, S. (2008). A relational account of public health ethics. In Public Health Ethics (pp. 1, 3, 196-209).

Committee to Advance Ethical Decision Making in Community Health. (2001). Final Report March 2001-December 2001. Toronto: Community Access Care Centre Toronto.

Dawson, A. (2010). Theory and Practice in Public Health Ethics: A Complex Relationship. In A. Hann, & S. Peckham (Eds.), Public Health Ethics and Practice. London: Policy Press.

Elpern, E. H., Covert, B., & Kleinpel, R. (2006). Moral distress of staff nurses in a medical intensive care unit. In Am J Crit Care (pp. 523-30).

Global Forum on MSM & HIV (MSMGF) (2012) MSMGF Strategic Plan 2012 – 2016 from http://www.msmgf.org/files/msmgf/Publications/strategicplan_20122016.pdf

Ho, A. (2008). "Relational autonomy or undue pressure? Family's role in medical decision-making.". Scand J Caring Sci 22(1), 128-135.

International HIV/AIDS Alliance. (2009, December 23). Nigeria and Kenya Demonstrate the Power of Cross-Alliance Learning. Retrieved 2012, from AIDS Alliance: http://www.aidsalliance.org/NewsDetails.aspx?Id=459

International HIV/AIDS Alliance. (2010). Good Practice Guide: Integration of HIV and Sexual and Reproductive Health and Rights. Hove, England, UK.

International HIV/AIDS Alliance. (n.d). International HIV/AIDS Alliance. Retrieved 2012, from Alliance eLearning - Good Practice Guides: http://www.interactdev1.co.uk/alliance/SRH2/player.html

International HIV/AIDS Alliance, Commonwealth HIV & AIDS Action Group. (n.d). Briefing: HIV, Health and the Law, Commonwealth Health Ministers Tackle Legal Obstacles that Undermine Effective HIV Responses. Hove, England, UK.

Liaschenko, J. (1996). A sense of place for patients: living and dying. In Home Care Provider (pp. 270-2).

Liaschenko, J., & Peter, E. (2002). The voice of home care workers in clinical ethics. HEC Forum, 14(3), 217.

McCarthy, J., & Deady, R. (2008). "Moral distress reconsidered". Nurs Ethics, 15(2): 254-262.

Murphy, T. (2006). Ethics and CCHSA's Accreditation Program. Toronto: Joint Centre for Bioethics.
NGO Code of Good Practice. (2012). Guiding Principles. Retrieved 2012, from NGO Code of Good Practice:

http://hivcode.org/search-the-code/guiding-principles

NGO Code of Good Practice. (n.d.). Code of Good Practice for NGOs Responding to HIV/AIDS, Chapter 2: Guiding Principles.

Open Society Institute and Equitas - International Centre for Human Rights Education. (2009, March). HIV/AIDS and Human Rights - A Resource Guide. New York, NY, USA. Retrieved 2012, from Health and Human Rights: A Resource Guide: http://equalpartners.info/downloads_eng.html

Rushton, C. H. (2006). Defining and addressing moral distress: tools for critical care nursing leaders. In AACN Adv Crit Care (pp. 161-8).

Slowther, A., Bunch, C., Woolnough, B., & Hope, T. (2001). Clinical ethics support services in the UK: an investigation of the current provision of ethics support to health professionals in the UK. In J Med Ethics (p. (Suppl. I): i2).

Sokol, D. K. (2008). The "four quadrants" approach to clinical ethics case analysis; an application and review. J. Med. Ethics, 34; 513-516.

Talkington, S. (1995). Ethical issues in home care. HEC Forum, 7(5), 290.

Turoldo, F. (2010). "Relational autonomy and multiculturalism". Camb Q Healthc Ethics, 19(4): 542-549.

Twigg, J. (2000). Chapter 9: The power dynamics of care. In J. Twigg, Bathing - the body and community care (pp. 179-208). New York: Routledge.

UK Consortium on AIDS and International Development. (2011). HIV Care and Support Roadmap to Achieving Universal Access to HIV Care & Support by 2015. London, England, UK: UK Consortium on AIDS and International Development. Retrieved from http://aidsconsortium.org.uk

UNAIDS. (2011). Good participatory practice - Guidelines for biomedical HIV prevention trials 2011. Geneva: UNAIDS.

UNAIDS. (2011, November). HIV and Social Protection Guidance Note. Guidance Note 2011. Geneva, Switzerland.

UNAIDS. (2011). Key programmes to reduce stigma and discrimination and increase access to justice in national HIV responses. Geneva: UNAIDS.

United National Development Programme. (2012). Global Commission on HIV and the Law: Risks, Rights & Health. New York: UNDP, HIV/AIDS Group, Bureau for Development Policy.

Vangen, S., & Huxham, C. (2003). Nuturing Collaborative Relations - Building trust in inter-organizational collaboration. The Journal of Applied Behavioural Science, 39(1), 5.

Wojtak, A. (2002). Practise based ethics as a foundation for human resources planning in community health care. In Healthc Manag Forum (pp. 67-72).

World Health Organization/UNAIDS. (2013). HIV and Adolescents: Guidance for HIV Testing and Counselling and Care for Adolescents Living With HIV.

World Health Organization/UNAIDS. (2004). Guidance on ethics and equitable access to HIV treatment and Care. Geneva, Switzerland.

World Vision International. (n.d.). Self-Assessment Checklist: Children and HIV.

The Four-Step Tool

Ethical Decision-Making

1. Identify the Facts & Assumptions
2. Determine the Ethical Values & Principles in Conflict
3. Explore Options & Consider their Strengths & Weaknesses
4. Choose an Option, Take Action, Evaluate & Debrief

Before you start to go through the four steps, briefly describe the situation or issue(s) that you are trying to address by using this tool.

What is the situation or issue that you are having?

Is it really a dilemma, or is it a common service delivery problem? If it is a dilemma, is it an *ethical* dilemma? (If it is not an ethical dilemma, then using this tool may not be as helpful to you. If you are unsure about the answer to these two questions, consult page 15 of the guidance.)

STEP 1: The 4-Box Method to Identifying the Facts & Assumptions

Adapted from Jonsen, Albert, Siegler, Mark and William J. Winslade (2002) Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine, McGraw-Hill Medical; 5th edition.

In each of the four boxes, there are a number of questions to prompt you to think about what important information you need in order to make a decision about the issue(s) that you are facing. Some of these questions may not be relevant to the issue(s) that you are trying to address, but they are designed to help identify what you know as facts, what you don't know, what are assumptions, and where you need to find out more information.

Remember, it is not necessary to answer all of the questions.

Health, Care, & Support Needs:

For each client involved in the situation, think about the following questions, and answer as many as you think relevant:

What do you think the client's needs are (e.g., health including treatment and medications; care; support; social needs, etc.), and are there other people whose needs should be considered? What about potential risks and harms? What other facts do you need? Be careful about unduly consulting with family or medical personnel who may, or may not have the best interest of the client in mind.

Client Preferences in this Situation:

For each client involved in the situation, think about the following questions, and answer as many as you think relevant:

Have you talked to the client about this situation? What are the client's expressed preferences? Is there any reason to believe that the client does not have the ability to make decisions? If yes, who is the substitute decision maker? If no, are client's wishes informed, understood, and voluntary? Is the client's right to choose being respected?

Quality of Life:

For each client involved in the situation, think about the following questions, and answer as many as you think relevant:

How has the client described the current situation to you in the context of life generally? What would it mean to the client if you could meet the needs and preferences described? What difference would it make in the client's life? As a care worker, do you see it the same way? Consider emotions, feelings, values, biases and prior experiences of the people involved, including you. What are the consequences for you in supporting the client's preferences?

Contextual Issues:

For each client involved in the situation, think about the following questions, and answer as many as you think relevant:

What is the relevant social, economic, and/or institutional context? Are there organizational values to consider? What laws might have a negative impact on your client(s)? What laws might influence your response? Has anything changed recently that affects the situation? What other services are or could be involved? What plans have been put in place so far?

STEP 2: Determine the Ethical Values & Principles in Conflict

Now that you've identified the facts, identify the ethical dilemma(s). Which ethical principles are in conflict?

Refer to the list in the left column and to the full Code of Ethics and Ethical Values and Principles on pages 16-18. It may help to explain the issue(s) first by using the facts from Step 1, and then to identify the ethical values and principles that correspond to the issue(s). State the ethical dilemma by explaining which ethical values and principles are in conflict – there may be more than two.

Circle the relevant ethical values & principles below:	**Explain the Issue(s):**
• ***Dignity*** • ***Diversity*** • ***Advocacy*** • ***Security*** • ***Quality*** • ***Accountability*** • ***Privacy*** • ***Confidentiality*** • ***Managing Conflicting Obligations*** • ***Fair and Equitable Access*** • ***Health and Wellbeing*** • ***Informed Choice*** • ***Empowerment*** • ***Cooperation*** • ***Family*** • ***Prioritizing children while supporting parents in key populations***	
Based on Steps 1 & 2, what is/are the ethical dilemma(s)?	

STEP 3: Explore Options and Consider their Strengths and Weaknesses

Brainstorm all of the options that you can think of, even those that may not be ideal solutions. Brainstorm and discuss with peers as appropriate. Whenever possible, discuss the options with your client(s). Consider under what circumstance(s) you would not discuss the options with the client(s), and how you would justify that decision. Be creative and use your imagination. Consider a compromise. Think about the outcomes or consequences for each alternative. What is the good that might come of each option? What is the harm that might come of each option? Do the options you have developed fit with the client(s)'s/family's statement of values and preferences, and the information that you obtained from your client(s)? Question whether the alternatives meet relevant policies, directives and regulations. Make sure that you weigh the strengths and weaknesses of all of the options before you make a decision. Consider which options do the most good or the least harm. Consider what ethical principles each option upholds or what ethical principles each option violates. Consider also how practical it would be to act on each option.

Option:	Strengths:	Weaknesses:

STEP 4: Choose an Option, Take Action, Evaluate and Debrief

Develop an Action Plan *(The actual plan should be documented)*

Given all the information that you have, choose the best option(s) available. Present alternatives to the client(s) and those involved. Re-examine the options if other factors come to light, if the situation changes, or if the client does not agree. Develop an action plan that includes what you are going to do and the steps that you are going to take. Determine when to evaluate the plan. Document and communicate the plan.

THE PLAN IS:

Evaluate the Plan:

What was the outcome of the plan? How did the client(s) feel about how the issue was resolved? Is there need for further action?

Self-evaluate Your Decision and Debrief with Colleagues:

How do you feel about the decision and the outcome? What would you do differently next time? What would you do the same? What have you learned about yourself? What have you learned about this decision-making process? What can your organization learn from this situation? What changes can the organization make to better support people making similar decisions? What changes can the organization make to better address these types of situations?

POCKET GUIDES:

To Handling Ethical Dilemmas in the Field

1 STEP 1: SEPARATE FACTS FROM ASSUMPTIONS.

What are client(s)' health, care, and support needs? Preferences? Quality of life? What is the context? What are the things you know are facts? What are the things that you are assuming—and is your bias making you less objective? Is there anything else you need to find out?

2 STEP 2: WHAT ARE THE ETHICAL PRINCIPLES IN CONFLICT? WHY IS THIS AN ETHICAL DILEMMA?

Example: Confidentiality versus Health & Wellbeing

Example: Fair and Equitable Access versus Quality

3 STEP 3: EXPLORE OPTIONS AND CONSIDER THEIR STRENGTHS AND WEAKNESSES.

What are your options to address the ethical dilemma(s)? What good or what harm might come rom these options?

4 STEP 4: DECIDE ON THE OPTION THAT CAUSES THE MOST GOOD OR LEAST HARM.

How do you feel about this decision? How does the client feel? Do you need to talk to someone about this? Remember, if your first option doesn't work, revisit your other options.

1 STEP 1: SEPARATE FACTS FROM ASSUMPTIONS.

What are client(s)' health, care, and support needs? Preferences? Quality of life? What is the context? What are the things you know are facts? What are the things that you are assuming—and is your bias making you less objective? Is there anything else you need to find out?

2 STEP 2: WHAT ARE THE ETHICAL PRINCIPLES IN CONFLICT? WHY IS THIS AN ETHICAL DILEMMA?

Example: Confidentiality versus Health & Wellbeing

Example: Fair and Equitable Access versus Quality

3 STEP 3: EXPLORE OPTIONS AND CONSIDER THEIR STRENGTHS AND WEAKNESSES.

What are your options to address the ethical dilemma(s)? What good or what harm might come rom these options?

4 STEP 4: DECIDE ON THE OPTION THAT CAUSES THE MOST GOOD OR LEAST HARM.

How do you feel about this decision? How does the client feel? Do you need to talk to someone about this? Remember, if your first option doesn't work, revisit your other options.

1 STEP 1: SEPARATE FACTS FROM ASSUMPTIONS.

What are client(s)' health, care, and support needs? Preferences? Quality of life? What is the context? What are the things you know are facts? What are the things that you are assuming—and is your bias making you less objective? Is there anything else you need to find out?

2 STEP 2: WHAT ARE THE ETHICAL PRINCIPLES IN CONFLICT? WHY IS THIS AN ETHICAL DILEMMA?

Example: Confidentiality versus Health & Wellbeing

Example: Fair and Equitable Access versus Quality

3 STEP 3: EXPLORE OPTIONS AND CONSIDER THEIR STRENGTHS AND WEAKNESSES.

What are your options to address the ethical dilemma(s)? What good or what harm might come rom these options?

4 STEP 4: DECIDE ON THE OPTION THAT CAUSES THE MOST GOOD OR LEAST HARM.

How do you feel about this decision? How does the client feel? Do you need to talk to someone about this? Remember, if your first option doesn't work, revisit your other options.

1 STEP 1: SEPARATE FACTS FROM ASSUMPTIONS.

What are client(s)' health, care, and support needs? Preferences? Quality of life? What is the context? What are the things you know are facts? What are the things that you are assuming—and is your bias making you less objective? Is there anything else you need to find out?

2 STEP 2: WHAT ARE THE ETHICAL PRINCIPLES IN CONFLICT? WHY IS THIS AN ETHICAL DILEMMA?

Example: Confidentiality versus Health & Wellbeing

Example: Fair and Equitable Access versus Quality

3 STEP 3: EXPLORE OPTIONS AND CONSIDER THEIR STRENGTHS AND WEAKNESSES.

What are your options to address the ethical dilemma(s)? What good or what harm might come rom these options?

4 STEP 4: DECIDE ON THE OPTION THAT CAUSES THE MOST GOOD OR LEAST HARM.

How do you feel about this decision? How does the client feel? Do you need to talk to someone about this? Remember, if your first option doesn't work, revisit your other options.

[3] The ethical principles in this guidance, defined on pages 16-18, are: Dignity, Diversity, Advocacy, Security, Quality, Accountability, Privacy, Confidentiality, Managing Conflicting Obligations, Fair and Equitable Access, Health and Wellbeing, Informed Choice, Empowerment, Cooperation, Family, and Prioritizing children while supporting parents or caregivers in key populations.