

# Ensuring Privacy and Confidentiality in Reproductive Health Services



## A Training Module and Guide for Service Providers



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## Foreword

The individual's right to privacy is highly valued, widely endorsed, and routinely violated. Although many international agreements and national laws and policies recognize and uphold the right to privacy, many individuals would be surprised to know that they even have such a right. The protection of privacy is crucial in reproductive health (RH) programs and especially critical in the field of HIV/AIDS, where stigma, discrimination, and violence can result from disclosure of HIV status. Without trust that health information will remain confidential, men, women, and youth from all over the world fail to seek the testing, care, and treatment they need.

The right to privacy can only be maintained if health providers and others who interact with clients in a health delivery setting develop and fully implement policies to protect confidential information. When an individual shares personal health information with a provider, he or she relies on the good will of the provider. Clients appreciate assurances of confidentiality, but are less forthcoming and honest if they do not trust such assurances. Proper care and treatment require accurate information.

Just as clients are often unaware of their rights to privacy, many providers are similarly unaware of their personal obligation to protect these rights. Consequently, health personnel may violate the client's rights unwittingly or carelessly, unaware of the severe repercussions that may ensue for breaching the client's right to confidentiality. Because "privacy" and "confidentiality" remain largely undefined in operational terms, training is needed to help providers uphold their ethical, moral, and legal obligations to the client. Many training manuals refer to the need to ensure privacy and confidentiality but fail to specify the actions needed to do so.

In response to a growing concern over the consequences of the lack of privacy and confidentiality for women and disadvantaged groups, Dr. Elaine Murphy, in her capacity as PATH's former Director of the Women's Reproductive Health Initiative, initiated the effort to develop a training guide to provide clarity and practical guidance to empower frontline RH workers and supervisors enabling them to develop and implement effective privacy and confidentiality policies. PATH supported this work through core RH grants.

This guide considers the constraints to protecting privacy in low-resource settings and provides an evidence-based rationale that services will be more effective if resources are invested in ensuring the privacy rights of clients. The Global Health Council is pleased to contribute to the publication and distribution of this guide as part of our effort to inform and improve health practices on the basis of sound research and policies. We at PATH and the Global Health Council hope that this guide will enable providers and supervisors not only to have a better understanding of their personal and professional responsibilities, but also to practice new behaviors that demonstrate respect, empathy, and commitment to protecting the privacy rights of clients.

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# OVERVIEW

## Why is privacy and confidentiality needed in reproductive health programs?

In order to provide appropriate and high quality reproductive health (RH) services, including counseling, providers must ask clients a range of sensitive questions about their sexual behavior or that of his or her partner. Clients are less likely to reveal accurate information if they fear that personal information will be shared with anyone other than the health provider. Clients have sensitive and diverse needs, such as testing and treatment for sexually transmitted infections (STIs), including HIV, treatments to prevent mother-to-child transmission of HIV, family planning, and care for complications of unsafe abortions. A growing body of research supports that protection of privacy and confidentiality is a priority factor in whether clients access RH information, counseling, and services. When clients experience violations in privacy or confidentiality they are also more likely to drop out of services. Adolescents are particularly reluctant to seek services when they think that confidentiality may not be maintained (American Academy of Pediatrics 1989, 1996; Allen 1997; Senderowitz 1997; UNFPA 1999). A provider's failure to observe a client's rights to privacy and confidentiality can mean delays in early diagnosis and treatment, incomplete treatment when clients drop out of services, or clients seeking questionable care from unqualified people. Poor health outcomes resulting from both social stigma and related psychological trauma are well documented.

## What is privacy and confidentiality?

Because the right to privacy cannot be respected unless confidentiality is observed, the two are often coupled and thought of as a single right—e.g., “the right to confidentiality and privacy.” Yet, the two are not one and the same.

The World Health Organization (WHO) defines **privacy as a personal right** and **confidentiality as a duty**, in this case, on the part of providers.

**Privacy** is “the right and power to control the information (about oneself) that others possess” (WHO 2000b). Privacy also commonly refers to the privacy of a person and the rights of individuals not to be physically exposed against their will.

**Confidentiality** is “the duty of those who receive private information not to disclose it without the patient's consent” (WHO 2000b). Confidentiality is the mechanism through which the client's right to privacy is protected.

To this end, WHO recommends that those offering clinical and counseling services 1) provide a private space for examinations, treatment, and counseling; and 2) respect client confidentiality by not telling others what clients revealed during the session or even whether the client received services.

Elements of privacy include **visual** privacy and **auditory** privacy. Visual privacy includes protection from unnecessary bodily exposure, which may occur during a physical examination. No one who is unnecessary to the procedure or examination should be allowed into the exam room without the explicit permission of the client. The client must agree to any compromise of her/his right to privacy. For example, to bring an observer in the room, the provider must comply with the client's wishes. Auditory privacy means that, to the extent possible, individual consultations should be conducted in private and out of earshot of others, including children, spouses, parents, family, friends, teachers, and neighbors.

Confidentiality means that the provider has an obligation not to reveal any information about a client without her/his consent. Any information held by a provider that has to do with a client's sexual or reproductive life is part of the client's private life, and therefore, the provider is obligated not to divulge this information to anyone other than the patient (IPPF 1995). Clients have the right to the assurance that information given to a provider will not be shared with others, even those involved in their care. This includes:

- Not gossiping about the client in the clinic or in the community.
- Keeping confidential documents about clients in a secure place.
- Not asking the client personal questions in the presence of other clients or non-health staff.
- Not insisting on spousal or parental consent.

### **How does the international community support a person's right to privacy and confidentiality?**

The right to privacy is a basic human right that is guaranteed by international standards. It is legally protected, cannot be waived or taken away, and is universally applicable (WHO 2002). The **Universal Declaration of Human Rights** (Article 12, 1948) states that no one shall be subjected to arbitrary interference with his privacy, family, home, or correspondence, nor to attacks on his honour and reputation. The **International Covenant on Civil and Political Rights** (ICCPR 1966) built on the Universal Declaration of Human Rights in stating "no one shall be subjected to arbitrary or unlawful interference with his privacy, family, home, or correspondence, nor to unlawful attacks on his honour and reputation" (Article 17).

Other international conventions including the **Covenant on Economic, Social, and Cultural Rights** (CESCR 1966), the **Convention on the Elimination of All Forms of Discrimination against Women** (CEDAW 1979), and the **Convention on the Rights of the Child** (CRC 1989) have ratified the right to privacy as a basic human right in health care. Almost every country in the world has signed at least one of these documents (WHO 2002). The right to privacy is interrelated with other human rights such as the right to health and information that States in the United Nations are obligated to protect.

Privacy and confidentiality have long been identified as two important elements of high quality, client-centered RH programs (Bruce 1990; Huezo and Diaz 1993; Murphy 2002). International conferences have been held to confirm basic rights to privacy in RH services. In 1994, **The Programme of Action** resulting from the **International Conference on Population and Development** (ICPD) held in Cairo, urged governments "to secure conformity to human rights and ethical standards in the delivery of family planning and related reproductive health services"



(7.17), stipulating, “privacy and confidentiality should be ensured” (7.23). With regard to adolescent clients, the ICPD document noted specifically that services must safeguard the rights of adolescents to privacy, confidentiality, respect, informed consent, respecting cultural values, and religious beliefs (7.45).

**The Fourth World Conference on Women** held in Beijing in 1995, adopted similar language supporting the provision of confidentiality and privacy to children as well as adults. It states that, “[Governments should] [re] design health information, services and training for health workers so that they are gender-sensitive and reflect the user’s right to privacy and confidentiality” (Paragraph 106[f]). In 1999, the Key Actions Document resulting from the **ICPD + 5** conference reinforced that, “Governments...should develop and implement national HIV/AIDS policies and action plans, ensure and promote respect for the human rights and dignity of persons living with HIV/AIDS...[and] enact legislation to ensure nondiscrimination against people living with HIV/AIDS and vulnerable populations, including women and young people so that they are not denied the information needed to prevent further transmission and are able to access treatment and care services without fear of stigmatization, discrimination, or violence.”

Other documents refer extensively to the ethical obligations of providers towards clients and the human rights of clients for ethical treatment including confidentiality and privacy. A list of these Human Rights Declarations can be found in the Background Documents section of this guide.

### **Why is guidance on how to ensure privacy and confidentiality needed?**

An experience of disrespectful treatment can quickly tarnish the reputation of a service delivery site within a community. It is important to establish a strong ethic of treating all clients with dignity and respect, regardless of their differences in socio-economic, educational, or other perceived status measure. Respectful client treatment will greatly help make services acceptable to members of the community and will encourage clients to use needed services and follow through with treatment regimens.

Yet it is well known that privacy and confidentiality are routinely violated. During a study in Zimbabwe observations of client-provider interactions revealed that 23 percent of the interviews could be overheard, visual privacy was lacking in 32 percent of client interviews, and another staff member interrupted more than a third of the sessions (Kim et al. 1997). Young women are often reluctant to seek STI services in the Philippines because in some clinics vaginal smears take place in front of other women waiting for testing. In Honduras and Egypt, providers have been known to invite whomever they choose into a room to observe what they are doing. Thus, visitors have witnessed births, abortions, intrauterine device (IUD) insertions, counseling sessions, and pelvic examinations without the consent of the client.

As evidence continues to mount that violations of confidentiality and privacy routinely occur, or that the fear of such violations keeps people away from needed services, it has become more apparent that staff, providers, and supervisors lack understanding, information, and tools to deal with the ethical and practical issues of ensuring confidentiality and privacy in RH settings. The International Planned Parenthood Federation (IPPF) has recognized that the rights of the client,

including the right to privacy, engender a compensatory need for the provider to be trained in order to uphold these rights (IPPF 1995).

While most RH training curricula and clinical protocols now mention the need to protect clients' rights to confidentiality and privacy, few, if any, go beyond this mention to include specific exercises to help providers understand what is operationally meant by privacy and confidentiality. Providers and staff, such as receptionists, outreach workers, etc. need clear information about what constitutes privacy and confidentiality and practical ways to protect privacy and maintain confidentiality in their health care settings. Furthermore, supervisors responsible for monitoring the observance of these practices need guidance on how to deal with breaches of confidentiality and privacy or how to develop policies to handle such violations.

### **What is the purpose of this guide?**

*Ensuring Privacy and Confidentiality in Reproductive Health Services: A Training Module and Guide for Service Providers* is designed to enable clinic staff, service providers, and supervisors to better support and protect the right of clients to privacy and confidentiality. It is divided into three parts:

- 1) A **Training Module** that includes interactive exercises, activities, and case studies designed to help health care staff, providers, and supervisors to:
  - Make an emotional connection to the issue of personal privacy and the client's right to control information about himself or herself.
  - Practice ways to uphold international standards of privacy and confidentiality.
  - Develop strategies for ensuring privacy and confidentiality in their local health care settings.
  - Define breaches in privacy and confidentiality and develop a plan to handle these violations.
- 2) **Job aids** that can be used during the training to improve participant knowledge and skills. The job aids can serve as a reminder of actions needed to protect privacy and maintain confidentiality while providing RH services.
- 3) **Background Documents** that provide extensive documentation and a list of resources related to privacy and confidentiality, as well as useful information for supervisors and policy makers who are responsible for developing and implementing organizational or government policies regarding private and confidential health services. These include:
  - Language from international agreements and covenants that concerns the right to privacy and the duty to protect this right through confidential services.
  - The ethical and moral basis for the human right to privacy.
  - Examples of how governments and organizations have dealt with conflicts in rights, e.g., between adolescent and parental rights, and an explanation of the "mature minor" doctrine.<sup>1</sup>
  - Recommendations from expert groups.

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<sup>1</sup> In the United States, the "mature minor" doctrine provides a legal basis for physicians to grant rights to mature adolescents to seek treatment without the knowledge or consent of their parents.

## **Who should use this guide?**

**Trainers:** The Training Module is designed for training frontline staff, health providers, and supervisors on privacy and confidentiality. If all health center employees attend privacy and confidentiality training then they can discuss and agree upon the standards that each must uphold, as well as identify what the consequences will be for breaching confidentiality. There are special exercises for supervisors and managers on how to support privacy and confidentiality, how to set policies for such support, as well as how to handle breaches of information.

While it may be feasible and desirable to involve all staff in a single training, differences in educational level, literacy, and job responsibilities can make this impractical. Therefore, agendas for different staff levels are provided. The exercises can be conducted together in a separate four-hour session or incorporated into larger RH training programs.

**Frontline staff, health care providers, and supervisors:** Job aids in the form of checklists are provided to help those who see, hear, or interact with RH clients, to help them ensure privacy and maintain confidentiality on the job.

**Supervisors and policy makers:** Several of the training exercises and activities can be used to raise awareness among supervisors, policy makers, or other influential leaders, providing critical information on the need to set and adhere to standards of privacy and confidentiality and how to address or set policies for handling violations of these standards. The background documents can also be used to garner support for setting privacy and confidentiality standards in health care settings and for setting policy on handling privacy and confidentiality breaches, and for providing adequate resources to implement these practices in the clinical setting.



# Training Module



## Pre-Workshop Checklist

- ❑ Read the introductory material and annexes before giving the workshop.
- ❑ Arrange the workshop site.<sup>2</sup>
- ❑ Arrange to have the following equipment available for the workshop:
  - Two flipchart stands
  - Newsprint (flipchart paper) on the flipchart stands and loose for small group work
  - Markers
- ❑ Prepare flipcharts for the different exercises (see “Preparation” under each individual exercise).
- ❑ Make enough copies of the job aids for each participant in the workshop.
- ❑ Make enough copies of the case studies for each participant for the practice session.
- ❑ Make enough copies of the Participant Evaluation Form for each participant.
- ❑ Arrange to have refreshments, if resources permit.

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<sup>2</sup> If the training is conducted off-site from where services are provided, it is important to keep in mind that off-site training can have a number of drawbacks. These might include:

- Those most in need of training may not be sent to participate.
- Training may take place in an environment that is not similar to the clinic setting, making it more difficult for staff in low-resource settings to envision how the lessons and logistical evaluation can be applied to their own environment.
- Home-based staff who do not attend may be resistant to changes introduced by those that do, or may not claim ownership of the principles that are essential to maintaining higher standards of quality.





## **Sample Agenda for a Workshop with Frontline Staff and Service Providers**

8:00 – 8:10	Introduction
8:10 – 8:30	Secrets
8:30 – 8:50	Privacy: A Human Right
8:50 – 9:00	Privacy and Confidentiality: Not One and the Same
9:00 – 10:00	Ensuring Privacy and Confidentiality
10:00 – 10:30	Breaches in Privacy
10:30 – 10:50	Break
10:50 – 11:10	Handling Breaches in Privacy and Confidentiality
11:10 – 12:10	Practice/Case Studies
12:10 – 12:30	Next Steps



## **Sample Agenda for a Workshop with Medical Officers, Supervisors, and Managers**

8:00 – 8:10	Introduction
8:10 – 8:30	Privacy: A Human Right
8:30 – 8:40	Privacy and Confidentiality: Not One and the Same
8:40 – 9:10	Breaches in Privacy and Confidentiality
9:10 – 9:30	Handling Breaches in Privacy and Confidentiality
9:30 – 9:45	Break
9:45 – 10:15	Supporting Privacy and Confidentiality
10:15 – 11:15	Practice /Case Studies
11:15 – 11:30	Next Steps



## Facilitator Tips: Using Good Facilitation Skills

- **Let the participants know that you are paying attention to them:**
  - ✓ Face the participants (eye to eye).
  - ✓ Look at everyone—scan the entire group.
  - ✓ Smile at individuals.
  - ✓ Nod affirmatively—encourage participation.
  - ✓ Walk toward participants.
  
- **Observe how the training is being received and adjust your training method accordingly.**

<b>If you notice that participants are:</b>	<b>Then:</b>
<b>Bored</b>	<ul style="list-style-type: none"> <li>➤ Speed up the pace.</li> <li>➤ Take a break.</li> <li>➤ Stop talking and let participants talk or practice.</li> <li>➤ Use different training techniques, such as role plays, case studies, lectures, small group work, etc.</li> </ul>
<b>Confused</b>	<ul style="list-style-type: none"> <li>➤ Ask questions to clarify.</li> <li>➤ Give examples.</li> <li>➤ Have others in the group explain the topic.</li> <li>➤ Demonstrate.</li> <li>➤ Let participants practice and provide hands-on assistance, if necessary.</li> </ul>
<b>Sleepy</b>	<ul style="list-style-type: none"> <li>➤ Make sure the room is not too warm or stuffy.</li> <li>➤ Make sure there is enough light.</li> <li>➤ Use a variety of training methods and training aids.</li> <li>➤ Take a break.</li> </ul>
<b>Inattentive</b>	<ul style="list-style-type: none"> <li>➤ Stop talking and ask questions.</li> <li>➤ Have participants practice and exercise.</li> <li>➤ Ask others to explain a topic.</li> <li>➤ Speed up the pace.</li> <li>➤ Change your training technique.</li> <li>➤ Take a break.</li> </ul>

□ **Listen to participants:**

- ✓ Encourage participants to talk and listen to the words they use and the feelings they express.
- ✓ Paraphrase what was said to demonstrate understanding.

□ **Ask questions:**

- ✓ Use open-ended questions to elicit discussion, learn how training is being received, invite feedback, etc.
- ✓ Use close-ended questions for a more limited response.

**How to handle difficult questions:**

- Acknowledge the effort of the participant, regardless of the type of question.
- Minimize potential embarrassment for wrong or inappropriate question(s) by deferring inappropriate question(s) to the break period.
- Ask the group to answer the participant's question.
- Defer prolonged discussions for the break.

## **Introduction**

**Time:** 10 minutes

### **Instructions:**

1. Introduce yourself and other co-facilitators, if appropriate.
2. Have participants introduce themselves and explain their role in the health clinic.
3. Mention that this session is on how to protect the privacy and maintain the confidentiality of clients when providing RH services.
4. Ask participants what they would like to learn about privacy and confidentiality. (*Note:* List responses on flipchart paper.)
5. Explain that by the end of this session, participants will be able to:
  - a) Articulate the difference between privacy and confidentiality.
  - b) Describe ways to ensure privacy and confidentiality during delivery of RH services.
  - c) Define breaches in privacy and confidentiality and describe how to handle them.





## Secrets

**Time:** 20 minutes

### Preparation:

Prepare a newsprint (flipchart) page with two columns—the first column labeled “Feelings” and the second column labeled “Consequences.”

### Instructions:

#### A. Telling secrets

1. Have participants think of a secret in their lives.
2. Ask them to write down one or more reasons why they might reveal this secret to someone. (*Note:* Emphasize that they do not have to tell the secret.)
3. After a few minutes ask participants what their reasons for revealing the secret were. (*Note:* List responses on the flipchart.)
4. Add any of the following, if not mentioned by participants:
  - It is natural/tempting to tell your friend/best friend/spouse everything.
  - I wanted advice on what to do about a problem that someone else confided in me.
  - I wanted to look important—“I know something you do not.”
  - I just let it slip—I forgot it was secret information.
  - I felt pressured into telling it.
  - Someone asked if I knew about the situation and I did not want to lie.
  - I wanted to hurt somebody I do not like; get revenge on someone who has hurt me.
5. Reassure participants that it is natural to want to confide in someone for the many reasons that they just discussed.

#### B. Revealing Secrets

1. Ask participants how they would **feel** if they confided their secret in someone and that person told the secret to someone else without their permission.
2. List responses on the flipchart paper under the column labeled “Feelings.”
3. Ask what might be the **consequences** of telling their secrets to other people without their permission. (*Note:* List responses under the column labeled “Consequences.”)

4. Mention that health care providers often need to ask clients sensitive questions about their sexual behavior in order to offer the best counseling, treatment, contraceptive method, etc.
5. Ask how a client might feel if sensitive information about him or her were revealed to another person who did not need to know the information.
6. Compare the responses with the participants' list of feelings.
7. Ask what would be the **consequences** of revealing this sensitive information to others.
8. Ask how the consequences would affect the health center, the client's health, the provider's reputation, etc.
9. Mention that revealing private information about a client to someone else without the authorization of the client is a violation of the client's rights.
10. Explain that a client is entitled to know his/her provider is not allowed to give any of his/her information to anyone else without his/her written permission.

## Privacy: A Human Right

**Time:** 20 minutes

### Preparation:

- ❑ Familiarize yourself with the declarations and conventions mentioned below. (See the Background Documents section.)
- ❑ On newsprint (flipchart) paper, prepare the following list of declarations that support the right to privacy and confidentiality:
  - Universal Declaration of Human Rights (1948)
  - International Covenant on Civil and Political Rights (1966)
  - Covenant on Economic, Social, and Cultural Rights (1966)
  - Convention on the Elimination of All Forms of Discrimination Against Women (1979)
- ❑ Prepare a newsprint (flipchart) page with the following list of declarations that support privacy and confidentiality as a basic human right in RH care:
  - Convention on the Rights of the Child (1989)
  - International Conference on Population and Development (ICPD) (1994)
  - The Fourth World Conference on Women (1995)
  - ICPD + 5 (1999)
  - United Nations Declaration of Commitment on HIV/AIDS (2001)
  - UNAIDS: HIV/AIDS and Human Rights, International Guidelines (2002)
- ❑ Make enough copies of the “Background Documents” for each participant in the workshop.

### Instructions:

1. Ask participants what a right is.
2. Ask for some examples of basic rights that we have as individuals, for example, the right to free speech, the right to practice your own religion, the right to vote, the right to live where one chooses, etc. (**Note:** These rights may vary by country.)
3. Explain that a client is entitled to privacy as a basic human right and that this right is supported by international human rights declarations, which are agreements that governments of the world have agreed to uphold in their countries.

4. Briefly review the following declarations (listed on flipchart paper) and point out the aspects that support privacy as a human right:
  - Universal Declaration of Human Rights (1948)
  - International Covenant on Civil and Political Rights (1966)
  - International Covenant on Economic, Social, and Cultural Rights (1966)
  - Convention on the Elimination of all Forms of Discrimination Against Women (1979)
5. Explain that every country in the world has signed at least one of these documents (WHO 2002), which obligates those who live and work in these countries to protect these rights.
6. Mention that international conferences have since been held to confirm basic rights to privacy in RH services.
7. Briefly review the following declarations and conventions and highlight sections that support privacy and confidentiality in RH services:
  - Convention on the Rights of the Child (1989)
  - ICPD (1994)
  - Fourth World Conference on Women (1995)
  - ICPD + 5 (1999)
  - United Nations Declaration of Commitment on HIV/AIDS (2001)
  - UNAIDS: HIV/AIDS and Human Rights, International Guidelines (2002)
8. Emphasize that privacy and confidentiality are one of several universal rights, and it is our responsibility as health providers to protect this right, especially for women and groups that have less power in societies to demand their rights.
9. Explain that it is important to know about the declarations that support a client's legal and ethical right to privacy and confidentiality.
10. Ask what health care providers can do to meet these obligations, such as ensuring that all clinic staff knows about the essence of these declarations and their own responsibility to uphold them. (*Note*: List responses on a flipchart.)
11. Emphasize that the way to uphold these human rights is to ensure a client's privacy and by maintaining confidentiality of client information.

## Privacy and Confidentiality: Not One and the Same

**Time:** 10 minutes

### Preparation:

- Prepare a newsprint (flipchart) page with the definitions of “Privacy” and “Confidentiality” (see definitions below).

### Instructions:

1. Explain that privacy and confidentiality are not one and the same.
2. Ask participants what privacy is. (*Note:* List responses on a flipchart.)
3. Discuss the World Health Organization’s (WHO) definition of privacy. (*Note:* Have the definition prepared on a flipchart beforehand.)

**Privacy** is “the right and power to control the information (about oneself) that others possess” (WHO 2000b). Privacy also commonly refers to respecting the rights of individuals not to be physically exposed against their will.

4. Initiate a discussion around participant definitions of privacy and WHO’s definition. Mention, for example, that a right entitles each person, whether a health provider or a poor client, to determine what information about his/her own health status can be given to another person, including a parent, a spouse, or another health provider. Come to an understanding on what privacy means.
5. Ask participants what confidentiality is. (*Note:* List responses on the flipchart.)
6. Discuss WHO’s definition of confidentiality. (*Note:* Have the definition prepared on a flipchart beforehand.)

**Confidentiality** is “the duty of those who receive private information not to disclose it without the patient’s consent” (WHO 2000b). Confidentiality is the mechanism through which the provider protects the client’s right to privacy.

7. Initiate a discussion around participant definitions of confidentiality and WHO's definition. Mention that meeting this obligation requires that health workers must make sure that the rights of those with less power to act on their own behalf are protected. Come to a common understanding on what confidentiality means.
8. Review the differences between privacy and confidentiality and explain that the ways we ensure privacy are different from the ways we ensure confidentiality.
9. Mention that the next exercise will explain how to ensure privacy and maintain confidentiality.

## Ensuring Privacy and Confidentiality

**Time:** 60 minutes

### Materials needed:

- ✓ Newsprint (flipchart) paper for use during three to four small group discussions.
- ✓ Markers for three or four small groups.
- ✓ The following checklists from the Job Aids section of this guide:
  - *Ensuring Visual and Auditory Privacy: A Checklist for Providers*
  - *Ensuring confidentiality of Client Information: A Checklist for Providers*

### Preparation:

- Make a copy of the two checklists for each participant in the workshop.

### Instructions:

#### Ensuring Auditory and Visual Privacy

1. Explain that violations of a client's **auditory** privacy occur when other clients, family members, or other clinic staff overhears a conversation between clients and providers in which personal information is related or discussed.
2. Mention that **visual** privacy is violated when persons other than the health staff directly involved are able to see a client undressing, being examined, or in a one-on-one counseling session.
3. Explain that the purpose of this exercise is to brainstorm about ways to protect auditory and visual privacy when providing RH services.
4. Ask participants exactly what happens to clients from the moment they enter a health center to the moment they leave the health center.
5. Probe to get the exact steps a patient takes from the beginning to the end of his/her visit to the health center and all the staff he/she encounters along the way. (*Note:* On a flipchart, list the steps and every staff person that a client meets along each step of his/her visit.)
6. After the list is as complete as possible, ask participants to help you group the steps into three or four main areas (e.g., reception, patient screening, examination, counseling, check-out, etc.).

7. Divide participants into three or four small groups, based on the number of areas identified above. There should be a small group for each identified main area. (*Note:* Participants from different clinics may be grouped by clinic instead of by area. If participants work in settings without separate areas for these functions, two groups can be formed to discuss visual or auditory privacy.)
8. Ask participants in each small group to develop a list of specific ways they **currently** ensure privacy in their main area. The list should be written on flipchart paper and divided into the following two categories:
  - Ways they ensure auditory privacy (preventing conversations from being overheard, etc.).
  - Ways they ensure visual privacy (preventing clients from being seen).
9. Allow about 15 minutes for the small groups to develop their lists.
10. Ask each group to present its list.
11. After all the groups have presented, review the entire list of ways participants currently ensure auditory and visual privacy in their health center(s).
12. Distribute the job aid entitled, *Ensuring Visual and Auditory Privacy: A Checklist for Providers*, to all participants and review other things that could be done to ensure auditory and visual privacy during the delivery of RH services.
13. Remind participants to consider gender issues in privacy. Relate the following event (see box below) and ask if there are differences in the privacy needs of different client groups, such as women, adolescents, and men.

At Profamilia clinics in Colombia, receptionists often asked female clients sensitive questions in the presence of other patients. However, when Profamilia began providing services for men, the men did not tolerate being questioned by the receptionists in public. As a consequence, supervisors became more aware of how men will demand privacy but women may not (AVSC and Profamilia 1997).

14. Ask how the privacy rights of the poor, women, and adolescents can be better protected given their vulnerability and timidity in demanding their rights.

#### Maintaining Confidentiality

1. Ask the small groups to reconvene and develop a list of ways they currently maintain confidentiality of a client's information in their main areas.
2. Allow about 15 minutes for the small groups to develop their lists.



3. Ask each group to present its list.
4. After all the groups have presented, review the entire list of ways participants currently maintain confidentiality of a client's information.
5. Distribute the job aid entitled, *Ensuring Confidentiality of Client Information: A Checklist for Providers*, and initiate a discussion about other things that could be done to ensure confidentiality of information when providing RH services.
6. Ask participants what constraints exist to ensuring privacy and confidentiality in their RH programs.
7. Brainstorm about ways to overcome some of the constraints mentioned.
8. Wrap up the exercise by asking participants for some concrete actions they will take to better ensure privacy and confidentiality for their clients.



## Breaches in Privacy and Confidentiality

**Time:** 30 minutes

### Instructions:

1. Ask participants for examples of how an individual's privacy and confidentiality may be violated. (*Note:* List responses on a flipchart.)
2. Help participants to group their responses into **internal** (within the clinic) and **external** (outside the clinic) breaches of privacy and confidentiality.
3. Add the following examples of **internal** violations, if not mentioned by participants:
  - Speaking to a client about a health condition, test results, or sexual behavior in the presence of others.
  - Allowing unnecessary personnel or visitors into an examination or surgical room.
  - Gossiping among staff about the client within the clinic.
  - Having unauthorized staff look at client records.
4. Add the following examples of **external** violations, if not mentioned by participants:
  - Gossiping about a client in the community.
  - Sending confidential client information to others without the client's consent/authorization.
  - Notifying a client's partner or parents of his/her condition.
  - Seeking consent of the partner or parents for contraception or other RH care.
5. Ask what the impact on the individual is when his/her privacy is violated.
6. Cover some of the following, if not mentioned by participants:
  - Potential clients are unwilling to seek health treatment, including voluntary testing for HIV/AIDS, because they fear that the services are not confidential.
  - Clients drop out of service or treatment programs because of the lack of privacy during their previous visit.
  - Clients are more likely to provide inaccurate or incomplete information if they do not have confidence in or if they mistrust the health staff. And, in the absence of accurate information, providers cannot provide proper treatment or advice.

- Adolescents are less likely to seek services they need if they do not feel that confidentiality will be maintained. Fear that services will not be confidential is the number one reason why adolescents do not use RH programs.
  - Women at antenatal voluntary counseling and testing (VCT) sites refuse to be tested for fear that an HIV-positive result would lead to job loss, ridicule, retribution, or abandonment by spouses, parents, families, friends, community members, or religious leaders.
  - Infants become infected with HIV because HIV-positive mothers fear to be tested, or to seek or accept treatment to prevent parent-to-child transmission.
  - Wives are physically or verbally abused by family members for getting contraception without the members' permission.
  - A client does not receive contraception and becomes pregnant.
  - A client loses his/her job when his/her HIV status is disclosed.
7. Brainstorm about what the impact of these breaches would have on the provider and/or the health clinic.
8. Add any of the following, if not mentioned by participants:
- A husband threatens the provider who gave his wife contraceptives without his consent.
  - A provider or clinic's reputation declines.
  - A clinic steadily loses its clientele because people do not trust its staff.
  - A clinic loses revenue and has poor health care statistics.
  - A provider's job satisfaction declines.
9. Discuss the impact that breaches in privacy and confidentiality have had in different countries.
- In Indonesia, a woman can be turned away from emergency obstetrical services because her husband is not present to give permission.
  - In Africa, persons known or suspected of being HIV-positive have been beaten. In one well-publicized event, a woman was beaten to death for revealing her HIV status.
  - In northern Ghana, a study found that 51 percent of women and 43 percent of men said a husband has the right to beat his wife if she uses contraception without his permission. Women ask for injectable contraceptives so they can conceal contraceptive use from their husbands (Bawah et al. 1999).
  - In Africa, many women are unwilling to be tested for HIV or to take anti-retroviral (ARV) drugs to prevent parent-to-child transmission of HIV for fear of being rebuked, abandoned by their partners, or stigmatized by their family and community.

- In Tanzania (Dar es Salaam) one in four women in a study of women who sought VCT services for HIV/AIDS said, “Violence is a major part of my life.” Fear of a violent reaction from a partner was the main reason that women gave for not revealing their test results to their partners (Maman et al. 2001).
- A study in Zimbabwe found that the great majority of interviewed service providers believed that parents should be notified if a young unmarried client was pregnant, had HIV, or engaged in sex at an “early” age. Half of these providers believed that parents should be notified if their unmarried child requested family planning services. Providers’ attitudes justified the fears of youth that they could not seek confidential services (Kim et al. 1997).
- In many countries clients are jeopardizing their own health or that of their partner or unborn child out of fear that their right to privacy will be violated.

10. Ask participants how they can prevent such events from happening at work and in their communities.



## Handling Breaches in Privacy and Confidentiality

**Time:** 20 minutes

### **Instructions:**

1. Explain that the requirement to respect the rights of clients can only be maintained if there are consequences for not doing so.
2. Discuss the differences between **unintentional** and **intentional** breaches.

#### Examples of **unintentional** breaches:

- A staff member enters a room thinking it is empty while a partially dressed patient is being examined.
- Non-medical staff inadvertently overhears a conversation between medical staff consulting about a client's condition.
- A visitor to the health center sees another person's health information on the reception desk or on the computer.
- A client is observed in the waiting room of a clinic that provides sensitive health services (e.g., abortion, STI treatment, VCT, etc.)

#### Examples of **intentional** breaches:

- Gossiping about a client in the community.
  - Sending confidential client information to others without the client's authorization.
  - Notifying the partner or parent(s) of a client's condition.
  - Seeking consent from a partner or parent for contraception or other RH services.
  - Walking into an exam room knowing that another health provider is examining a client.
  - Bringing an unauthorized visitor into an examination room before getting the client's consent.
3. Remind participants that acting carelessly is not the same as doing something unintentionally (i.e., a provider leaving a door open when counseling an HIV-positive client is an intentional act based on known requirements for privacy. This is not the same as when a provider

unintentionally walks into a VCT counseling session to get supplies from the room, thinking that the room was empty).

4. Ask participants for examples of breaches in privacy and confidentiality that happen in their health center(s).
5. Ask participants how these breaches in privacy and confidentiality are handled in their health center(s). (*Note*: List responses on a flipchart.)
6. Initiate a discussion around how consequences would differ between **unintentional** and **intentional** violations.
7. Ask how and to whom breaches of confidentiality should be reported.
8. Ask who determines what the consequences will be—staff, supervisors, government, management, etc.
9. Ask whether their health center has any written policies on how breaches in privacy and confidentiality should be handled.
10. Inquire how policies are set for handling breaches in privacy and confidentiality.
11. Ask how the staff at their health center is made aware of these policies.
12. Ask what kinds of policies still need to be in place at their health center.
13. Ask what participants can do to ensure that policies for handling breaches are properly developed and upheld.



## **Supporting Privacy and Confidentiality (for medical officers, supervisors, and managers)**

**Time:** 30 minutes

### **Preparation:**

Make enough copies of the job aid entitled, *Supporting Client Privacy and Confidentiality: A Checklist for Supervisors and Managers*, for each participant in the workshop (see the Job Aids section of this guide).

### **Instructions:**

1. Ask participants for ways that supervisors/managers can support privacy and confidentiality in their health settings. (*Note:* List responses on a flipchart.)
2. Ask for ways that supervisors/managers can help staff protect the privacy and confidentiality of clients.
3. Ask how supervisors/managers can ensure that health center staff is protecting a client's right to privacy and confidentiality.
4. Ask participants to describe the role of supervisors/managers in handling breaches of privacy and confidentiality.
5. Ask how intentional and unintentional violations are handled in their setting.
6. Ask who determines the consequences for breaches in privacy and confidentiality.
7. Ask how the following are handled in participants' respective health centers:
  - Disclosing adolescent pregnancy or abortion to parents.
  - Disclosing the STI status of one partner to another being treated by the same provider.
  - Requiring a woman seeking contraception to obtain her husband's consent.
  - Disclosing the results of a positive HIV test to a client when proper counseling mechanisms are not in place.
  - Finding confidential client records in a place where other staff or clients may view them.
  - Hearing a receptionist ask a client a personal question in the presence of others.
8. Ask what current policies are in their sites for handling the situations mentioned in # 7 above.
9. Discuss the differences, if any, which exist between policies and actual practice.

10. Explain that some providers, for example, are unaware of privacy and confidentiality laws and assume that they are required to notify parents when an adolescent seeks contraception or a pregnancy test. Others “take the law into their own hands” and apply their own cultural or religious standards when serving adolescent clients.
11. Ask how supervisors/managers should handle situations where discrepancies exist between policy and practice—where rules exist to protect privacy and confidentiality but health staff do not actually behave according to the rules.
12. If policies are needed, ask who sets these policies and how supervisors and managers can influence them.
13. Ask how health center staff can be made more aware of privacy and confidentiality policies and how the policies can be better enforced.
14. Distribute the job aid entitled, *Supporting Client Privacy and Confidentiality: A Checklist for Supervisors and Managers*, and discuss ways that some of the action items are implemented or could be implemented in the participants’ health centers.
15. If participants have not already received them, distribute the following two job aids:
  - *Ensuring Visual and Auditory Privacy: A Checklist for Providers*
  - *Ensuring Confidentiality of Client Information: A Checklist for Providers*

## Practice

**Time:** 60 minutes

### Preparation:

There are three case studies for providers and one specifically for supervisors and managers. Depending on the composition of the participants, make enough copies of the appropriate case studies for each small working group in this exercise.

### Instructions:

1. Divide participants into three or four groups, depending on the composition and/or number of participants in the training.
2. Distribute a different case study to each group. If there is a group of supervisors and managers, be sure to give them “Ntare’s Story” and/or “Ashok’s Story.”
3. Ask them to read their case study and answer the related questions.
4. After about 20 minutes (or when participants are ready), have each group present their case study and the answers to the questions.
5. After each small group’s presentation, initiate a discussion about the group’s responses to the case study and ask other participants how they might have responded to the case’s situation.
6. After all the groups have made their presentations, ask which participant suggestions are applicable in their own clinic(s). (**Note:** List responses on a flipchart.)



### **Case Study: Laxmi's Story**

Laxmi, an illiterate housewife, is a mother of five children; four daughters and a son. Her youngest baby is four months old. Her husband Ram is a laborer with poor wages. She does not want any more children and wants to use a family planning (FP) method. Ram and her mother-in-law do not agree; they insist that Laxmi try again to have one more son.

Laxmi visits the village health center one day using the excuse that she has a headache. She does not inform her mother-in-law or her husband of the real purpose of the visit. At the health center, there is no private counseling room. Rita, the service provider, counsels Laxmi on various available FP options in the presence of other waiting clients. Laxmi chooses an intrauterine device (IUD), thinking she can conceal the method from her husband. Another client overhears the conversation between Laxmi and Rita.

Word gets back to Laxmi's mother-in-law that Laxmi has an IUD, and the mother-in-law is furious that Laxmi got a method over her objection. She tells her son and together they verbally abuse and beat Laxmi. They force her to return with them to the health center immediately. They confront Rita, demanding that she remove the IUD. All the while, they scold Laxmi for concealing the reason for her visit to the health center and disobeying them. They also scold Rita for helping Laxmi in this decision and for not consulting them. They forcefully take Laxmi back home, where she is ostracized, has food withheld from her, and is given extra work to do.

#### **Discuss the following questions:**

1. How could this incident have been avoided?
2. Rita was willing to give Laxmi a method, without telling her husband or mother-in-law, thus respecting Laxmi's right to privacy. Was this correct?
3. Is it Rita's fault if she does not have a private space to counsel Laxmi? What could Rita have done differently?
4. Should Rita be disciplined for violating Laxmi's auditory privacy and if so, what should be the consequence?
5. What issues do the provider/supervisor/manager need to address in this case?
6. What impact will this incident have on the health center?



## **Case Study: Jana's Story**

Jana is a 15-year-old student. She arrives at the local outpatient hospital, accompanied by a friend, and asks to see the doctor. After a long wait, Jana finally sees the doctor. Jana's friend explains that she is concerned because Jana has been sick and vomiting. The doctor immediately asks when Jana had her last menstrual period. When Jana says she cannot recall, the doctor is very critical. He examines her without speaking, fills out a pregnancy and blood test form, and hands them to her, telling her to go to the laboratory and return the following morning. He does not explain the nature of the tests.

Jana is worried and comes the next day with her mother. The doctor informs them both that Jana is pregnant. The mother had not known the reason for Jana's visit and is furious with her. She begins to yell at Jana and tells her how disappointed she is in her. The doctor tells Jana to return in two months for antenatal care.

A few days later, Jana is admitted to the hospital during the night with fever, anemia, and hemorrhaging. Her parents are not with her. The nurse learns that her friend helped her find an untrained abortionist. Although legal abortion is available in the country, Jana was afraid to be seen by another medical person. When she developed a fever and was losing a lot of blood, her friend brought her to the hospital. Before her parents can be notified of her grave condition, Jana dies of blood loss and infection.

### **Discuss the following questions:**

1. Why did this happen?
2. How could it have been avoided?
3. What could the doctor have done differently?
4. Should the provider be disciplined for violating Jana's privacy and if so, what should be the consequence for this?
5. What other measures can the clinic take other than disciplinary action?
6. What impact will this incident have on the clinic?





## Case Study: Maria's Story

While Maria was able to complete the eighth grade, there is no work for her in the village where she lives. Her parents are very poor, and she wants to help them out, so she moves to the capital city to find more employment opportunities. Unable to find a job right away, she reluctantly turns to sex work as a means to support herself and her family.

Maria knows that condoms can protect her from STIs and unwanted pregnancy, but many of her clients refuse to use condoms. She needs the money so she agrees to have sex without a condom. One day a peer educator talks to her about the symptoms of STIs and tells her where she can get screened and treated for STIs, if she ever has any symptoms. Maria confides in her that she is, indeed, having a discharge and mentions that she is interested in going to the clinic. Besides, she wants to ask the clinic personnel about how to prevent pregnancy. The peer educator suggests that she go to the clinic the following day where she will counsel her. Unfortunately, Maria's *mamasan*<sup>3</sup> will not let her off for a couple of nights because there are a lot of customers.

A couple of days later, Maria goes to the clinic and in the presence of other clients, is asked by the receptionist what she is there for. She explains her concerns in a soft voice and is told to wait for an examination. She is taken into the exam room where the doctor is performing a pelvic exam on another girl in the presence of her and other girls waiting in the room. Maria recognizes some other sex workers and is humiliated by this experience. The next time she has symptoms, she avoids returning to the clinic until she becomes seriously ill and is taken to the hospital.

### Discuss the following questions:

1. Why did this happen?
2. How could it have been avoided?
3. Should the doctor be disciplined for violating Maria's privacy and if so, what should be the consequence for this?
4. What measures can the clinic take other than disciplinary action?
5. What impact will this incident have on the clinic?
6. What impact will this incident have on the spread of STIs, including HIV?

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<sup>3</sup> An Asian colloquialism meaning the manager and boss of sex workers.



**Case Study: Ntare's Story  
(for supervisors and managers)**

Ntare lives in a small village where the main source of income comes from raising cows and goats. She is pregnant with her third child. Her husband is away a lot working in another district to supplement the family's meager income.

While at the antenatal clinic the nurse tells Ntare that she will be doing blood tests to determine if she has malaria, syphilis, or HIV. The nurse explains the risks of malaria and syphilis to both the unborn baby and her and encourages her to take the test. She also talks to the mother about the importance of being tested for HIV so that she will know her status. The nurse explains that if a pregnant woman is HIV-positive, she and her baby can receive medicine that will help protect the baby from becoming infected. Ntare is scared but decides to take the tests.

While in the waiting room, before she has received her test results, she overhears the nurse tell another nurse that Ntare's HIV test was positive. Ntare is so horrified about her status and ashamed that other people now know that she is HIV-positive that she leaves the clinic and never returns. Ntare delivers her baby at home with a traditional birth attendant. The baby is born HIV-positive and neither the baby nor Ntare have the care and treatment they need for their illness.

**Discuss the following questions:**

1. If this case were brought to the supervisor, how should she/he handle it?
2. What should the consequences be for this lack of confidentiality?
3. How could this have been avoided?
4. What kinds of policies need to be in place to avoid such incidences?
5. What can supervisors/managers do to ensure that the confidentiality of a client's information is maintained?
6. Besides disciplinary actions, what can supervisors/managers do to encourage providers and frontline staff to maintain the confidentiality of a client's information at **all** times?
7. What can the clinic do about Ntare's situation?



### **Case Study: Ashok's Story (for supervisors and managers)**

Ashok comes from a middle class family. His father is a doctor. He has known that he is attracted to men since he was an adolescent. He has had a number of partners but for some time has been seeing only one man. Since reaching his twenties, his parents have been putting pressure on Ashok to marry and have children. They now want to arrange a marriage with another family. Ashok believes that as the only son, he will need to marry to satisfy his parents, even though he will continue to see his partner.

Ashok's partner has been feeling unwell and decides to be tested for HIV. When he learns he is positive, he suggests that Ashok also should be tested. Ashok goes to a VCT center where he is also diagnosed as HIV-positive. At the VCT clinic another doctor who is a friend of the family recognizes him. The doctor has access to Ashok's test results, and learns that Ashok is HIV-positive. He decides to tell Ashok's father in the hopes that he can help Ashok get treatment, which is expensive but not beyond the reach of Ashok's family.

Ashok's father has had suspicions that Ashok was gay and confronts him about his HIV status. Ashok is remorseful that his father knows and that he will not be able to marry and win the approval of his parents. He is angry with the doctor who revealed his status to his father and files a complaint with the VCT center.

#### **Discuss the following questions:**

1. If this case were brought to the medical supervisor, how should she/he handle it?
2. What should the consequences be for this lack of confidentiality?
3. How could this have been avoided?
4. What kinds of policies need to be in place to avoid such incidences?
5. What can supervisors/managers do to ensure that the confidentiality of a client's information is maintained?
6. Besides disciplinary actions, what can supervisors/managers do to encourage providers and frontline staff to maintain the confidentiality of a client's information at **all** times?



## Next Steps

**Time:** 10 minutes

### **Instructions:**

1. Review the list of things that participants said they would like to learn about privacy and confidentiality from the Introduction exercise.
2. As you review each item, ask participants whether they feel that they have learned enough about the privacy and confidentiality issues that they are interested in.
3. Brainstorm about ways that participants can get the information or support that they need for issues that remain.
4. Ask participants what they will do differently as a result of this workshop. (*Note:* List responses on a flipchart.)
5. If it is possible to do so, tell participants that the list of action items noted on the flipchart will be typed up and distributed to all workshop participants.
6. Thank participants for their valuable participation and suggestions and encourage them to help others to learn more about how to ensure privacy and confidentiality.
7. Ask participants to complete an evaluation form.





## Participant Evaluation Form

1. Please mark the box that most appropriately reflects how you feel about each exercise.

### **Secrets**

- Very Good
- Satisfactory
- Needs Improvement

Suggestions for improvement

### **Privacy: A Human Right**

- Very Good
- Satisfactory
- Needs Improvement

Suggestions for improvement

### **Privacy and Confidentiality: Not One and the Same**

- Very Good
- Satisfactory
- Needs Improvement

Suggestions for improvement

### **Ensuring Privacy and Confidentiality**

- Very Good
- Satisfactory
- Needs Improvement

Suggestions for improvement

### **Breaches in Privacy and Confidentiality**

- Very Good
- Satisfactory
- Needs Improvement

Suggestions for improvement

### **Handling Breaches in Privacy and Confidentiality**

- Very Good
- Satisfactory
- Needs Improvement

Suggestions or comments

### **Supporting Privacy and Confidentiality** (for medical officers, supervisors, and managers)

- Very Good
- Satisfactory
- Needs Improvement

Suggestions or comments

### **Practice and Case Studies**

- Very good
- Satisfactory
- Need improvement

Suggestions for improvement

2. What skills did you learn or improve upon?
  
3. What will you do differently as a result of this training?
  
4. What changes, if any, will you implement in your clinic as a result of this learning?

# **Job Aids**



## **Ensuring Visual and Auditory Privacy: A Checklist for Providers**

### **Provider Behavior**

#### Visual privacy

- ❑ Honor clients' right to privacy.
- ❑ Place a "Do Not Disturb" sign on the door to discourage others from entering while counseling or examining a client.
- ❑ Ask the client's permission before bringing in another health professional for consultation or observation of the client.
- ❑ Ask permission before bringing in the husband, mother-in-law, other family members, etc.
- ❑ Give contraceptive supplies or medications in a private area out of sight and earshot of others.
- ❑ If possible, use universal precautions (i.e., wearing gloves, safe disposal of sharps and sharps containers, etc.) with **all** clients to reduce calling attention to a particular client.
- ❑ Never visit the client at home without his/her permission.
- ❑ If making a home visit, ask the client if he/she would like to talk to you away from the others so they cannot see you.

#### Auditory Privacy

- ❑ Call out or announce the name of the client to be seen, but **never** the type of service he/she is receiving.
- ❑ Never ask a client in the presence of others what he/she is being seen for.
- ❑ If others are present, find a private place to ask a client sensitive information.
- ❑ Speak in a soft voice so that others **cannot** hear you.
- ❑ Always close the door when talking to a client.
- ❑ Discontinue interviews if an unauthorized person enters the room.
- ❑ Never discuss a client's exam or test results out loud where others can hear.

- ❑ Never call out or otherwise reveal a client’s HIV status to co-workers. If HIV status must be revealed to a doctor or other health professional for medical reasons, do so only under complete auditory privacy.
- ❑ If making a home visit find a place to talk where others cannot hear the conversation.

## **Health Center Design**

### Services and space

- ❑ In integrated services, do not distinguish family planning or STI/HIV/AIDS services from other services so that the purpose of the client’s visit will not be obvious to others.
- ❑ Use symbols (colors, flowers, numbers, etc.) to indicate where different clients should go. Do not label rooms with the names of the distinct services.
- ❑ Inform the client of the health center’s policy on privacy and confidentiality via brochures or posters placed in the health center.
- ❑ If possible, create client routes that produce one-way traffic to avoid jams and crowded areas where clients can be overheard.<sup>4</sup>
- ❑ Arrange an alternative site for partner/couple counseling if men express unwillingness to attend a family planning clinic.

### Reception area

- ❑ Post a statement or poster where clients can readily see it to inform clients of their right to privacy and the health center’s policy on protecting confidentiality.
- ❑ Use sign-in procedures that do not distinguish between types of services, such as one sign-in page for all services.
- ❑ Use numbers or other anonymous symbols to refer to clients in the filing system.
- ❑ Place materials on STIs, including HIV, together with materials about other health topics so that attention is not drawn toward a person looking at particular materials.

### Counseling and/or examination area

- ❑ Create private space for taking health histories and providing counseling, such as a booth, a screened off area, or a separate office to improve visual privacy.

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<sup>4</sup> Management Sciences for Health. “Making your building work.” *Managing Quality & Clinical Services. The Manager online* (<http://erc.msh.org>).

- ❑ Designate a private place for the client to be in after getting his/her test results, and allow him/her time to compose him or herself if the results evoke an emotional reaction.
- ❑ If a client is referred for another service, ask the client to complete an informed consent form that authorizes the health center to disclose the client's health information to the referral center.
- ❑ Provide a door, curtain, or screen in the examination area to protect clients from being seen while they get dressed and undressed.

*Note:* While a movable partition provides visual privacy, this is not generally adequate for auditory privacy.

- ❑ Move the examination table out of view or use a curtain or screen between the door and the examination rooms. Be sure that a client can move from the examination area to the dressing area without being seen by others.
- ❑ Arrange examination tables in the exam rooms to avoid exposing private parts if someone accidentally opens a door or walks in while a person is being examined. For example, place the exam table facing away from the door or window.
- ❑ Use frosted or thick glass or a curtain/screen to block windows in the examination/dressing area.

## **Policies and Procedures**

- ❑ If private spaces do not exist, advocate for private rooms for examining and counseling patients, especially for STIs, including HIV, and AIDS testing and counseling.
- ❑ Provide childcare apart from the counseling room for children over age three so that they do not overhear their parent's conversations.
- ❑ Post a statement regarding standards of privacy for all providers to see. Make staff aware of consequences of violating the client's rights.
- ❑ Train all health center staff, outreach workers, and volunteers on the moral and legal issues surrounding privacy and confidentiality and how to ensure privacy and confidentiality at all levels of RH service delivery.
- ❑ If test results must be sent to clients by mail, use blank envelopes that do not have the name of the testing center on them, since other people, such as post office workers or family members, may see the envelope before the client does.
- ❑ Establish protocols for privacy and policies for breaches.





## **Ensuring Confidentiality of Client Information: A Checklist for Providers**

### **Provider Behavior**

- ❑ Look out for the client's best interests, recognizing that some clients, particularly poor women and adolescents, have difficulty understanding their rights.
- ❑ Honor the client's right to privacy and observe the provider's duty to protect information about the client.
- ❑ Always assure clients of privacy and that the confidentiality of all information including his/her visit will be protected. Explain how the information will be used and that this information will not be disclosed to another person without the client's permission.
- ❑ Never coerce a client to give consent to release information.
- ❑ If a client has been seen at a health center, take care not to inadvertently disclose that information to a parent or partner during the client's subsequent visit.
- ❑ Call the client into a private counseling room to discuss test results. Never mention test results or the availability of test results out loud.
- ❑ Obtain authorized consent from the client before disclosing information to any other person, including husbands, parents, other family members, or to other organizations.
- ❑ Do not mention the reason to schedule a return visit or anything else related to the nature of the client's visit in the presence of other clients.
- ❑ Keep the purpose of the client's visit and any personal information about a client or his/her test results confidential. Do not reveal this to others within or outside of the clinic.
- ❑ Do not gossip about a client to co-workers, family members, or friends.
- ❑ For adolescents: life-threatening, emergency conditions may require parental notification. In non-life-threatening situations, providers must carefully weigh the potential harmful consequences for the adolescent before deciding to inform his/her parent(s). Follow international guidance or local laws on adolescents right to privacy.
- ❑ Never visit the client at home without his/her permission.

### For STI/HIV/AIDS clients

- ❑ Obtain a client's permission before notifying his/her partner(s) if STI/HIV/AIDS results are positive. Do not notify the partner(s) without the client's permission. Encourage the client to inform his/her partner(s) and offer assistance.
- ❑ Offer clients the opportunity to have couple's counseling but give the test results to each partner separately. Allow him/her to decide whether to share the results with his/her partner.
- ❑ If laws exist for mandatory partner notification or reporting of STIs, including HIV, test results, inform the client what is done with the information collected about him/her before the test is given. Give the client the opportunity to consent to proceed or to withdraw from being tested.

### **Health Center Design**

- ❑ Place schedule books or computer screens or other places for appointments away from view of other clients.
- ❑ Keep personal medical records and information in a locked drawer or file cabinet, or provide a space where they can be locked up.
- ❑ Set up confidential record-keeping systems, such as using numbers instead of client names.
- ❑ If a client's record must have his/her name on it, organize the patient files by a number system, not an alphabetical system. This added layer of security makes it more difficult for an unauthorized person to find a file using the client's name.
- ❑ For STI or HIV testing, assign a unique identification number that is attached to the test in the presence of the client before the sample is submitted for testing. Then give the client the number so that the client's name and test results will be separate.
- ❑ If test results must be sent to the client by mail, do not include the name of the testing center on the return address, since other people, such as post office workers or family members, may see the envelope before the client does.

### **Policies and Procedures**

- ❑ Establish policies on the use and disclosure of a client's personal health information.
- ❑ Develop clear and specific protocols for private and confidential services and for addressing breaches of confidentiality.
- ❑ Ensure that all providers and others who interact with clients understand these protocols and agree to uphold them.

- ❑ Set up a system for monitoring how confidential procedures are being followed.
- ❑ Deal decisively with breaches in confidentiality.
- ❑ Limit access to patients' files and records to only staff that needs to know this information in order to treat the patient.
- ❑ Institute consent forms so that only clients authorize the release of their own medical information.
- ❑ Ensure that consent procedures (e.g., obtaining informed consent for a procedure or informed authorization of release of information) are strictly adhered to.
- ❑ For referrals to other services, ensure that other health centers/organizations receiving a client's information have policies in place that protect the confidentiality of information.
- ❑ Develop policies for treating adolescents and ensure that all personnel are aware of these policies.
- ❑ Keep providers informed of the legal requirements related to minors and other minority groups.



## **Supporting Client Privacy and Confidentiality: A Checklist for Supervisors and Managers**

### **Supervisor Behavior**

- ❑ Treat clients with dignity and respect.
- ❑ Never discuss clients in the open.
- ❑ Knock and/or ask permission to enter a room when staff is working with a client.
- ❑ Ask client's permission before observing staff performing an examination or consulting with a client.
- ❑ Encourage providers to always ask a client's permission for another person to enter the room while he/she is being examined or counseled.
- ❑ Recognize that vulnerable clients, e.g., youth, poor women, and indigenous people, may have little understanding of their rights. Encourage staff to be especially committed to protecting the rights of vulnerable clients.
- ❑ Respect that health workers are also entitled to privacy; do not reprimand a health worker in front of others for a breach of privacy or confidentiality. Take them aside to discuss it privately or follow the acknowledged clinic protocol.

### **Staff Support**

- ❑ Make respecting privacy and confidentiality a specific requirement in each staff person's job description.
- ❑ Make sure every person who has contact with clients or information about clients has a specific role in ensuring privacy and confidentiality, and knows how to do it.
- ❑ Make sure all employees have a clear understanding of their responsibilities to protect privacy and confidentiality, and ask them to sign a statement that they will uphold this commitment.
- ❑ Create incentives for staff that exemplify good practice in privacy and confidentiality. For example, integrate this as part of "employee of the month" achievements or workstation performance.
- ❑ Use supportive supervision techniques to the extent possible, e.g., compliment staff for treating clients with respect and observing proper procedures to protect confidentiality.

- ❑ Analyze client flow with staff at each station to identify points where privacy and confidentiality may not be protected, and discuss possible solutions.
- ❑ Make posters or job aids at each point in the client flow to remind staff how to protect privacy and confidentiality. Reinforce the concepts and practices through ongoing supervision and evaluation.

## **Policies and Procedures**

- ❑ Make policies that respect a client's rights and that maximize client safety, such as personal choice in deciding about parent or partner notification, or choosing a treatment option.
- ❑ Remove policies that create barriers such as requiring a woman to have her husband's permission for contraception or notifying a parent if an adolescent seeks reproductive health services at your health center.
- ❑ Take action as soon as possible if a violation of privacy or confidentiality occurs. Policies are not useful unless they are enforced.
- ❑ Deal with early breaches in a supportive manner as staff learns their responsibilities.
- ❑ Create consequences for violations of privacy and confidentiality, as with other performance problems, such as suspension or demotion, for serious breaches.
- ❑ Post a statement in waiting rooms and examining rooms indicating that the clinic observes the client's right to privacy and confidentiality.
- ❑ Get community input on how to improve and protect privacy and confidentiality through interviews and meetings with local nongovernmental organizations and community members and implement their suggestions.

# **Background Information**





## Human Rights Declarations Referencing the Right to Privacy and Confidentiality

The **Universal Declaration of Human Rights (Article 12, 1948)** states, “no one shall be subjected to arbitrary interference with his privacy, family, home, or correspondence nor to attacks on his honour and reputation” (<http://www.unhchr.ch/udhr/lang/eng.htm>).

The **International Covenant on Civil and Political Rights (ICCPR 1966)** built on the Universal Declaration of Human Rights (1948) in stating that “no one shall be subjected to arbitrary or unlawful interference with his privacy, family, home, or correspondence, nor to unlawful attacks on his honour and reputation” (Article 17) ([http://www.unhchr.ch/html/menu3/b/a\\_ccpr.htm](http://www.unhchr.ch/html/menu3/b/a_ccpr.htm)).

**The International Covenant on Economic, Social, and Cultural Rights (CESCR 1966)**, Article 12 explains that “The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health [and]...steps...to achieve the full realization of this right shall include those necessary for:

- (c) The prevention, treatment, and control of epidemic, endemic, occupational, and other diseases; (d) The creation of conditions, which would assure to all medical service and medical attention in the event of sickness ([http://www.unhchr.ch/html/menu3/b/a\\_ceschr.htm](http://www.unhchr.ch/html/menu3/b/a_ceschr.htm)).

**The Convention on the Elimination of All Forms of Discrimination against Women (CEDAW 1979)** states that “Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning” (Article 12) (<http://www.unhchr.ch/html/menu3/b/e1cedaw.htm>).

**The Convention on the Rights of the Child (CRC 1989)** has been ratified by all but two of the world’s governments. The guiding principle of the CRC is that in all actions concerning children, the best interest of the child is the primary consideration (CRC Article 3, UNICEF 1989). The CRC can be used to support that the best interests of the child are served when youth are provided with vital information on their sexual and reproductive health, as well as the means to protect themselves from unwanted pregnancy and STIs, including HIV and AIDS, without parental consent. Article 16.1 of the **Children’s Rights Convention** states, “No child shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence, nor to unlawful attacks on his or her honour and reputation” (<http://www.unicef.org/crc/fulltext-frameset.htm>).

**The Programme of Action resulting from the International Conference on Population and Development (ICPD 1994)** held in Cairo urged governments “to secure conformity to human rights and ethical standards in the delivery of family planning and related reproductive health services aimed at ensuring responsible, voluntary, and informed consent and also regarding service provision” (**Action 7.17**). **Action 7.23** states, “In the coming years, all family planning

programmes must make significant efforts to improve quality of care. Among other measures, programmes should:

...c.) Make services safer, affordable, more convenient, and accessible for clients and ensure, through strengthened logistical systems, a sufficient and continuous supply of essential high-quality contraceptives. Privacy and confidentiality should be ensured.

d.) Expand and upgrade formal and informal training in sexual and reproductive health care and family planning for all health-care providers, health educators, and managers, including training in interpersonal communications and counselling;...”

**Action 7.45** reinforces the need for privacy and confidentiality, “...services must safeguard the rights of adolescents to privacy, confidentiality, respect, and informed consent, respecting cultural values and religious beliefs.”

**The ICPD + 5 conference** in 1999 reiterated and reinforced action items and positions taken at the earlier conference:

**Paragraph 67**

“Governments...should develop and implement national HIV/AIDS policies and action plans, ensure and promote respect for the human rights and dignity of persons living with HIV/AIDS...[and] enact legislation to ensure nondiscrimination against people living with HIV/AIDS and vulnerable populations, including women and young people so that they are not denied the information needed to prevent further transmission and are able to access treatment and care services without fear of stigmatization, discrimination, or violence” (ICPD 1999).

**Paragraph 73**

“Governments, with the full involvement of young people and with the support of the international community, should....

(a) In order to protect and promote the right of adolescents to the enjoyment of the highest attainable standards of health, provide appropriate, specific, user-friendly, and accessible services to effectively address their reproductive and sexual health needs, including reproductive health education, information, counseling, and health promotion strategies. These services should safeguard the rights of adolescents to privacy, confidentiality, and informed consent, respecting their cultural values and religious beliefs and in conformity with relevant existing international agreements and conventions (ICPD 1999).

... (f) Countries should ensure that programmes and attitudes of health-care providers do not restrict the access of adolescents to appropriate services and the information they need, including for the prevention and treatment of sexually transmitted diseases, HIV/AIDS and sexual violence and abuse” ([www.unfpa.org/icpd/docs/index.htm](http://www.unfpa.org/icpd/docs/index.htm)).

**The Fourth World Conference on Women** held in Beijing in 1995 noted that confidentiality was often not afforded to women. The Platform of Action supports the provision of

confidentiality and privacy to children as well as adults: “[Governments should] [re] design health information, services, and training for health workers so that they are gender-sensitive and reflect the user’s perspective with regard to interpersonal and communications skills and the user’s right to privacy and confidentiality...” (Paragraph 106[f]).

(Paragraph 107[e]) of the same document notes that “[Governments should] [p]repare and disseminate accessible information...designed to ensure that women and men, particularly young people, can acquire knowledge about their health, especially information on sexuality and reproduction, taking into account the rights of the child to access information, privacy, confidentiality, respect and informed consent...”

“[Governments should] ensure...through the primary health care system...appropriate and affordable preventative services with respect to sexually transmitted diseases, including HIV/AIDS, and expand the provision of counseling and voluntary and confidential diagnostic and treatment services for women...” (Paragraph 108[m])

([www.un.org/womenwatch/daw/beijing/official.htm](http://www.un.org/womenwatch/daw/beijing/official.htm)).

## **Resources for Designing Policies and Programs for Privacy and Confidentiality with Respect to HIV/AIDS**

### **WHO/UNAIDS. *Key Elements in HIV/AIDS Care and Support: A Working Document.* Geneva: WHO/UNAIDS (2000).**

This document outlines key considerations and interventions for the provision of HIV/AIDS care and support in limited resource settings. The document identifies several principles and values that should be considered, such as, “Respect for human rights, ethics, confidentiality, informed consent, privacy, and individual dignity. Human rights and ethical practices apply equally to people living with HIV/AIDS (PLHA) as to other individuals. Fighting discrimination, enhancing respect of individual autonomy and human dignity, and pursuing informed consent are all relevant to HIV care and support.” Additionally, with respect to health system requirements for the care and support of PLHA the document states, “A conducive working environment is essential for delivery of good quality care. This would include: space, privacy, and staff time for voluntary counseling and testing (VCT) in general health services and for particular groups such as young people, antenatal services, operational procedures for patient care, for referrals to home care or enhanced care to ensure a care continuum and for universal precautions, and monitoring of coping capacity and adherence to standards to be put in place.”

The document also includes recommendations for policy development and legislation. It says, “Several relevant policies and regulations need to be formulated: e.g., HIV testing policies for diagnostic and clinical purposes at national and institutional levels, including professional codes, need to be reassessed to ensure confidentiality and disclosure policies of HIV testing and results provision, prevention of discrimination and stigma against PLHA in health settings...” ([www.unaids.org/publications/documents/care/general/WHOUNAIDSCARE.doc](http://www.unaids.org/publications/documents/care/general/WHOUNAIDSCARE.doc)).

### **United Nations Declaration of Commitment on HIV/AIDS (August 2001).**

“By [the year] 2003, [nations should] enact, strengthen, or enforce, as appropriate, legislation, regulations, and other measures to eliminate all forms of discrimination against, and to ensure the full enjoyment of all human rights and fundamental freedoms by, people living with HIV/AIDS...in particular to ensure their access to [services], while respecting their privacy and confidentiality; and develop strategies to combat stigma...” (Paragraph 58) ([www.unaids.org/whatsnew/others/un\\_special/Declaration2706\\_en.htm](http://www.unaids.org/whatsnew/others/un_special/Declaration2706_en.htm)).

**UNAIDS: HIV/AIDS and Human Rights, International Guidelines (Revised, Guideline 6, August 2002).** “States should enact or strengthen anti-discrimination and other protective laws that protect vulnerable groups, people living with HIV/AIDS and people living with disabilities from discrimination in both the public and private sectors, ensure privacy and confidentiality and ethics in research...” ([www.unaids.org/publications/documents/human/index.html](http://www.unaids.org/publications/documents/human/index.html)).

### **WHO. *Considerations for Formulating Reproductive Health Laws.* Geneva: WHO (2002).**

This report examines how laws can most effectively be developed to ensure protection for reproductive and sexual health. The report distinguishes the client’s right to privacy and the provider’s obligation to protect confidentiality. Included are case studies, exercises, and practical materials to deal with a broad spectrum of reproductive health issues from maternal mortality to

HIV/AIDS and sexual violence as well as incorporating gender and human rights into each module ([www.who.int/reproductive-health/gender/index.htm](http://www.who.int/reproductive-health/gender/index.htm)).

The **World AIDS Campaign 2002-2003** developed a conceptual framework and basis for action with respect to stigma and discrimination. One of the strategies for success is to “encourage practical HIV-related training for all health care workers to promote a better understanding, to promote confidentiality, and to reduce unfounded anxiety. The use of universal precautions will not only allay staff anxieties but will also help protect the identities and rights of infected patients” ([www.unaids.org/publications/documents/human/JC891-WAC%20framework\\_en.pdf](http://www.unaids.org/publications/documents/human/JC891-WAC%20framework_en.pdf)).

**Center for Reproductive Law and Policy. *Reproductive Rights are Human Rights*. New York: CRLP (2001).**

This booklet identifies ten human rights that are fundamental to reproductive rights. The document cites relevant international legal conventions to support these rights, one of which is the right to privacy ([www.reproductiverights.org/pdf/rrhr-english.pdf](http://www.reproductiverights.org/pdf/rrhr-english.pdf)).

**UNAIDS. *UNAIDS Report on the Global HIV/AIDS Epidemic*. Geneva: UNAIDS (July 2002).**

“This report provides positive proof that HIV/AIDS, if left to run its natural course, will cause devastation on an unprecedented scale.” The report offers many examples of success, case studies, and tools, which include human rights and gender perspectives ([http://www.unaids.org/Unaid/EN/Resources/Publications/Corporate+publications/Report+on+the+global+HIV\\_AIDS+epidemic+2002+.asp](http://www.unaids.org/Unaid/EN/Resources/Publications/Corporate+publications/Report+on+the+global+HIV_AIDS+epidemic+2002+.asp)).

**JHPIEGO. *Service Delivery Guidelines* [online]. **ReproLine. The Reading Room.****

Family Planning Service Delivery Guidelines can be found on The Reading Room’s Web site. They were developed in an attempt to standardize information for service providers by compiling existing information and consensus documents issued by the World Health Organization (WHO) and UNAIDS to establish one set of guidelines. The guidelines specifically mention maintaining privacy under quality of care for family planning programs. Under the counseling guidelines the document states the importance of privacy and confidentiality when serving clients ([www.reproline.jhu.edu/english/6read/6multi/sdg/index.htm](http://www.reproline.jhu.edu/english/6read/6multi/sdg/index.htm)).

**Commonwealth Medical Trust (Commat). *Training manual of ethical and human rights standards for health care professionals*. London: Commonwealth Medical Trust (2001).**

To address the need for linking medical ethics education to human rights, Commat has developed a training manual consisting of four modules with corresponding case studies. The concept behind each module is that health professionals participate in one module every year in order to renew their license to practice. The first module discusses issues related to privacy and confidentiality. The modules were pre-tested in a number of countries and can be downloaded from the Ethics section of Commat’s website (<http://www.commat.org/>).

## **The Ethical Basis for the Right to Privacy and the Duty to Protect Confidentiality**

Clients' rights to privacy and the duty of providers to protect this right through confidentiality derive from the principles that underpin the discipline of biomedical ethics and are recognized to be universally applicable by WHO (Beauchamp and Childress 1983)

These ethical principles are:

- a) **Respect for persons**, which includes both autonomy and the respect for self-determination of those who are capable of deliberating about their personal goals, and protection of persons with impaired or diminished autonomy.
- b) **Beneficence**, which is the ethical obligation to first do no harm and to maximize benefits and minimize risks or harm.
- c) **Justice**, which requires that clients are treated equally and that the less advantaged members of a community are not subject to violations of their rights to confidentiality and privacy based on their race, caste, class, gender, or age.

Several factors are to be considered when implementing these three ethical principles:

### **a. Respect for Persons**

Management and supervisors set the tone by the treatment they give to poor and vulnerable clients. By treating adolescent reproductive health clients or HIV-positive clients discreetly, with friendliness, and with reassurance of the confidential nature of their interaction, doctors and supervisors set an example of respectful treatment for the rest of the staff.

While providers must maximize the autonomy of the individual to direct his/her own health care, protection of persons with impaired or diminished autonomy obligates the provider to ensure the fair treatment of vulnerable clients—those who may not understand their rights, the implications of requests for informed consent, or of disclosure of sensitive information. Clients may be vulnerable based on lack of education or literacy, age, sex, gender, socioeconomic status, or health condition. The impairment may be temporary or permanent. For example, a person experiencing complications of an illegal abortion is in a particularly vulnerable state. The more disadvantaged the client, the more vulnerable and less able she is to act on her own behalf in seeking confidential, private, and respectful services, or of complaining when these rights are violated. This vulnerability imposes a greater responsibility on the part of the health organization to act as an advocate in protecting the rights of these clients to fair, impartial treatment, and good quality care (Ringheim 1999).

Clients may also be vulnerable due to immaturity. “The capacity for self-determination matures during an individual’s life. Respect for the immature may require protecting them as they mature” (The Belmont Report 1979). Thus, very young adolescents may be in need of protection

that the provider determines can only be provided by a parent. The provider is called upon to exercise considerable judgment and discretion when making a determination as to whether a young adolescent is capable of self-determination. “The extent of protection offered should depend upon the risk of harm and the likelihood of benefit” (Ibid., p. 4).

## **b. Beneficence**

Ethical duties to maintain confidentiality derive in part from the principle of “first, do no harm,” the basis of the Hippocratic Oath (often referred to as the principle of non-maleficence). This principle can be seen to take precedence even over the desire to maximize good over bad outcomes. (If there is no opportunity to do good, at least do no harm.) For example, in order to provide the proper treatment or advice, it is best if health providers know the relevant and often sensitive information about the client’s behavior and health status, including exposure to risk of HIV or unwanted pregnancy, experience of violence, and extramarital partners of the client or the client’s partner. At the same time, the disclosure of such sensitive information to others could harm the client.

If the provider cannot obtain sensitive information from the client in private, the provider should “first, do no harm” by not asking the client for information under these circumstances.

The advice that the provider gives is only as good as the information he/she has to go on. Fear that confidentiality will be breached is also a chief cause of failure to access needed services. If the provider cannot honestly assure the client that the information will be treated confidentially and no harm will come to the client by revealing it, the client is unlikely to be forthcoming and honest.

Benefits to clients are maximized and harms minimized when their rights are respected. Providers therefore should not engage in behaviors that decrease access to health services or that lessen the quality of health services that clients receive. In cases where the provider must make a choice between two actions, the one causing the least harm is the ethical choice. For example, in the case of the adolescent client, providers may experience a conflict between their duty to protect the privacy rights of the adolescent versus their felt obligation to inform the parent of the child’s health condition or behavior. However, to inform the parent may lead to unintended and even negative consequences for the child. In fact, the outcome cannot be known. The Hippocratic Oath requires physicians to benefit their patients according to their best judgment. If the provider can determine that the young person is capable of self-determination, the provider may strongly encourage the child to inform and involve the parent, but the final decision to inform the parent or not is left to the adolescent.

## **c. Justice**

Social injustice is the basis for much discrimination against women, and racial, ethnic, and sexual minorities. Client rights are human rights and do not differ regardless of the race, sex, sexual orientation, caste, class, religious, or educational status of the client. Research has documented the extent to which racial and sexual minorities are afforded diminished respect and attention to ethical standards of treatment by providers. An experience of disrespectful treatment

can quickly tarnish the reputation of a service delivery site within a community. It is important to establish a strong ethic of treating all clients with dignity and respect, regardless of the differences in socio-economic, educational, or other measure of perceived status that may exist within the staff of an organization. This respectful treatment will contribute greatly to making the services acceptable to members of the community and will encourage clients to utilize needed services, disclose confidential information, and follow through with treatment regimens.

Gender equity is also a matter of justice. Gender-based violations, both of women's rights to privacy and of providers' duty to maintain confidentiality are common. Laws or policies that infringe upon a woman's right to freely make decisions about her own body (e.g., access to contraception without the husband's knowledge or permission), violate her rights to autonomy and justice. Providers need to understand the specific vulnerability that gender power imbalances create for women whose rights to confidentiality are violated. Women whose reproductive health status is revealed to her partner, her parents, in-laws, or the community at large may be subjected to far worse than ostracism. Women must be protected from any pressure that their partners may place on providers to access confidential information. Women's heightened need for confidential services is one argument for providing women with access to STI testing and treatment within family planning settings, but this cannot be undertaken without ensuring that the necessary training and confidentiality protection mechanisms are in place.

In client-provider interactions involving a couple, providers have been found to defer to the male client (Kim et al. 2000). This also infringes on the female client's right to be treated equitably (Ringheim 2002). Training providers to be aware of gender dynamics is an important component of assuring that client-provider interactions uphold clients' rights.

Justice demands the equitable and fair treatment of all members of the community who seek or are eligible to seek health services. Providers may not discriminate against clients based on their health status, e.g., persons suffering from STIs, including HIV, women with complications of abortion, minors who are pregnant or seeking contraception, drug-users, or on the basis of the client's social status or profession (e.g., commercial sex worker).



## **The Legal Aspects of Privacy and Confidentiality**

There are three legal aspects of privacy and confidentiality (WHO 2000b):

### **1. The duty of providers to protect patient information against unauthorized disclosures.**

This obligates providers to obtain the client's permission before disclosing information about the client to others. In the event that providers are required by law to report cases of infectious diseases by name, the provider should respectfully make the client aware of this requirement. Policies should be in place to handle contingencies that health providers are likely to encounter in the course of their work. These may include disclosure policies for adolescent pregnancy; disclosure of one partner's STI status to another partner being treated by the same provider; or disclosure of infertility status to a spouse when such status may be grounds for divorce. Health providers and organizations dealing with such possibilities should have policies in place to guide staff when these situations arise. The WHO document referred to above (WHO. Considerations for Formulating Reproductive Health Laws. *WHO/RHR/00.1*. Geneva: WHO [2000b]) also suggests that providers' duty to confidentiality may extend to providing treatment that does not, by its visibility alone, violate the client's right to privacy. For example, if a woman desires to conceal her use of contraception from her husband, provision of an IUD or oral pills that can be felt or discovered, contravenes her wish to privacy in the use of contraception. However, providing her with an injectable method that cannot be detected would protect her private use of contraception (WHO 2000b).

### **2. Patients' rights to know the information that their providers possess about them.**

While patients do not have rights to the actual records that providers keep, they are entitled to control the information contained within them. Patients are entitled to information about themselves and providers are obligated to give patients "an adequate understanding for their purposes of information about their reproductive health" (WHO 2000).

This right must be handled judiciously, especially when the information could be damaging to the client. For example, this right argues in favor of the providers' obligation to disclose the results of a positive HIV test to the client, even when proper counseling mechanisms to help the client are not in place. Providers have sometimes withheld this information from the client on the grounds that the lack of counseling and social support may cause greater harm to the client than his/her HIV status. The client could potentially do harm to himself as a result of receiving this information. This right implies, however, that the client is entitled to know his/her status and that this right takes precedence over the provider's fear that the client won't be able to deal with the information in a responsible manner. Unless the client has the information that the provider possesses about his status, s/he cannot use that information to protect others. His/her right to autonomy is therefore violated.

### **3. Providers' duties to ensure that patients who authorize releases of their confidential information to others exercise adequately informed and free choice.**

Related to the requirement cited above, patients must know what information the provider knows in order to make an informed decision about releasing information to others. Providers should also consider whether their clients have an adequate understanding of how such disclosure may be disadvantageous to them. The more sensitive the information to be disclosed, the more important this becomes. For example release of medical information can lead to loss of employment or health insurance, loss of affection by the partner, or stigmatization. Providers are obligated to inform the client of the risks that they face in agreeing to release sensitive information to third parties. Providers should protect vulnerable clients, those who are unable to act in their own best interest, from harm that may come from release of confidential information that they authorize. Vulnerable clients may include those who are poorly educated or have low levels of literacy, women, adolescents, HIV positive persons, or those with complications from an abortion.

#### **The Provider's Obligation to Respect Legal Rights of Privacy and Confidentiality**

The client's right to privacy entitles him/her to have the maximum protection from unnecessary disclosure of personal information or exposure of person. Training should stress that under no circumstances are staff to succumb to pressure from any individuals to disclose confidential material without the express authorization of the client. This is particularly true of information related to sexual behavior, because of the interest that persons with power and authority over the subject may have in this information. Women, for example, must be protected from any pressure on the part of husbands to learn of their responses to personal and sensitive questions. Women and adolescents who seek confidential services should not be called by telephone or visited at their homes for follow-up without their explicit consent to be contacted at home.

#### **Applying Legal Rights of Privacy and Confidentiality to Minors and The Mature Minor Doctrine**

The legal standards that apply to adolescents are more complex. A key point of contention and debate is whether adolescents have rights to privacy and confidential treatment that override the right of a parent to be informed of a child's medical needs. Although laws and practices vary from country to country, in the United States, the "mature minor doctrine" provides a legal basis for physicians to grant rights to mature adolescents to seek treatment without the knowledge or consent of their parents. This is an important legal standard that has been used to defend the provision of services to adolescents ages 14 and over without consulting parents. The basis for selecting this age is developmental: reasoning ability is usually present by this age (Sigman and O'Connor 1991).

There are vast differences in the ways that the adolescent's legal right to privacy is interpreted by different governments. Because the rights of adolescents to private and confidential RH services are so contentious and are at the forefront of many national and international policy debates, the material that follows draws upon sources that help to clarify the language offered in international agreements concerning these rights.

**United States federal law** (Department of Health and Human Services/Office of Population Affairs (DHHS/OPA) Title X of the Public Health Services Act, 42 U.S. C.S. §§ 300 et. seq.) has stipulated since 1970 that federally supported family planning services are available to anyone who needs them regardless of age. Many states have adopted the “mature minor” rule and authorize adolescents to consent on their own to contraceptive services, testing and treatment for STIs, including HIV, and AIDS, prenatal care, treatment for alcohol and drug use, and outpatient mental health services. Adolescents can consent to testing and treatment for STIs in all 50 states. Contraceptive services for adolescents are more restricted than STI services, although states have expanded the rights of minors to consent over the past 30 years, reflecting rulings by the U.S. Supreme Court that extended the constitutional right to privacy to a minor’s decision to get contraceptives or terminate an unwanted pregnancy. In some states, physicians may inform the parents if they feel it is in the best interest of the adolescent to do so, but they are not required to do so (Alan Guttmacher Institute 2002a).

According to international law, children and adolescents enjoy the same human rights as adults. In 1994 the **International Conference on Population and Development’s (ICPD) Programme of Action** recognized that reproductive and sexual health “services must safeguard the rights of adolescents to privacy, confidentiality, respect and informed consent” (Paragraph 7.45). The ethical principles most applicable to providing confidential and private services to adolescents are autonomy and beneficence, the ethical obligation to maximize good and minimize harm.

**The Key Actions document resulting from the ICPD + 5** conference in 1999 specifically noted that countries should ensure that programs and attitudes of health care providers do not restrict the access of adolescents to appropriate services and information. Where necessary, legal and other barriers to RH information and services for adolescence should be removed (Haslegrave 2001). Many governments have made commitments to implement these international agreements with regard to adolescent RH. These governments have obligated themselves to respect the rights of adolescents, which may include providing them with education, counseling, and services.

**The Convention on the Rights of the Child (CRC)** has been ratified by 191 States (countries) and is the most widely adopted international human rights treaty in history (United Nations 2002) The guiding principle of the CRC is that in all actions concerning children, *the best interest of the child* is the primary consideration (CRC Article 3, UNICEF 1989). The CRC can be used to support that the best interests of the child are served when youth are provided with vital information on their sexual and reproductive health, as well as the means to protect themselves from unwanted pregnancy and STIs, including HIV, and AIDS without parental consent.

**Since 1989 the American Academy of Pediatrics (AAP)** has endorsed a policy of treating adolescents who seek health services with the same confidentiality as that afforded to parent/adults. (AAP 1989) The decision to involve the parent or not is complex, and the provider must be guided by the ethical obligations to protect autonomy, do no harm, and assure that benefits outweigh risks to the adolescent client. Concern about confidentiality is one of the primary reasons that young people delay seeking health care services for sensitive problems

(Allen 1997). Because parental involvement can lead to delay in treatment, non-treatment, and harmful consequences for the adolescent, the AAP asserts that the adolescent's right to confidential treatment is essential to avoid violating the principle of "do no harm." Further, AAP does not support legislation that would mandate parental consent or notification before an adolescent could get prescription drugs or contraceptive devices through federally aided programs, (The Family Planning Program authorized under DHHS/OPA Title X of the Public Health Service Act).

In terms of provision of contraception to those under age 16, **the British Medical Association, the Family Planning Association of Britain, and the Royal College of General Practitioners** go even further. Guidelines issued in 1993 to all practitioners in Britain indicate that disregarding the confidentiality of an adolescent's consultation for family planning is a serious breach of professional ethics. Young people are to be assured that they can put their trust in doctors (Sally 1993).

"On the one hand, it seems eminently reasonable that parents should have the right and responsibility to make health care decisions for their minor child. On the other hand, it may be more important for a young person to have access to confidential medical services than it is to require that parents be informed of their child's condition. Minors who are sexually active, pregnant or infected with a sexually transmitted disease may avoid seeking care if they must involve their parents. Recognizing this reality, many [US] states explicitly authorize minors to make decisions about their own medical care" (Alan Guttmacher Institute 2002b).

## **Considerations for Protecting the Rights of Adolescents to Private and Confidential Treatment**

Young people avoid known and accessible services due to feelings of discomfort with clinic conditions and real or perceived attitudes of providers. These feelings of discomfort result from fear of judgmental or hostile attitudes on the part of providers, and concerns over lack of privacy and confidentiality (Senderowitz 1999). Lack of confidentiality has been identified as the single most important factor in designing services for adolescents (Allen 1997). Adolescents are most concerned that information e.g., about their sexual behavior, substance abuse, or depression, will be shared with their parents (Ford 1998). A study conducted in the U.S. showed that the percentage of 15-24 year-olds willing to be tested for an STI fell from 92 percent if testing were confidential to 35 percent if parents would definitely find out that the test had been done (Ford 2001). Perceptions of, or direct experience with, lack of privacy and confidentiality may lead adolescents to seek services, such as treatment of STIs, from sources that are medically unsound. In Nigeria, lack of privacy was identified as a reason by 46 percent of adolescents surveyed, that they do not seek services in the public sector. Adolescents reported that they preferred traditional healers and private practitioners because these providers were more likely to guarantee them confidentiality (Copeland et al. 2002).

Some providers feel that their primary obligation is to inform and involve the parent rather than to protect the confidentiality of the adolescent client (Kim et al. 1997). It is clear that barriers must be overcome if adolescents are to use essential RH services, including pregnancy prevention, VCT for HIV and STIs, and treatment for STIs, including HIV. Many “youth-friendly” curricula focus on changing the critical and judgmental attitudes of health providers that discourage adolescents from seeking professional help at a time when they most need it. A key but often neglected aspect of this is that regardless how “friendly” the provider is, if the adolescent remains fearful that privacy will not be respected, she/he is unlikely to use the services or be forthcoming about sensitive information. Furthermore, it is harmful to the integrity of the program to assure adolescents that the consultation will be treated as strictly confidential if the firsthand experience of the adolescent or hearsay indicates otherwise.

Many countries, particularly in the wake of the HIV epidemic, have developed national youth policies that specifically endorse the rights of adolescents to receive confidential RH information and services. Some providers are unaware of the laws and assume that they are required to notify parents even if they are not. Others “take the law into their own hands” and apply their own cultural or religious standards to serving adolescent clients. In Zimbabwe, clients as young as 12-years old expressed concerns that their rights to privacy would be violated by providers. Interviews with providers substantiated the validity of these concerns. Of 127 service providers interviewed, 89 percent believed that parents should be notified if a young unmarried client was pregnant, 74 percent if the child had HIV, and 74 percent if the child engaged in sex at an “early” age (as determined by the provider). Half of all providers believed that parents should be notified if their unmarried child requested family planning services, and only 28 percent believed that youth under 16 should be given a contraceptive method (Kim et al. 1997).

Because the consequences of parental notification cannot be known in advance, providers must consider the possibility that this action may do more harm than good, even though the opposite

may be true. A strong argument in favor of protecting the rights of youth over the rights of their parents can be made on the basis that youth are contracting STIs, including HIV and AIDS, in record numbers.

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