

# Introduction

## Why This Tool Kit Is Needed

Early in 1999, EngenderHealth\* identified the need for a simple, practical job aid to explain, in concrete terms, the essential concepts that underpin informed and voluntary decision making in sexual and reproductive health (SRH). The need emerged through observations of family planning (FP) service programs in the field, and it was reinforced during discussions with U.S. Agency for International Development (AID) staff and implementing partners about carrying out the Tiahrt Amendment, a law enacted by the U.S. Congress in 1998 that went into effect in 1999, to protect voluntary FP acceptance.

The Tiahrt Amendment elevated several long-standing principles to the status of legal requirements in AID-funded programs. The amendment specifically prohibits establishing service quotas or targets, giving incentive payments to staff or method acceptors, and making rights or benefits contingent upon FP acceptance. The legislation also requires that FP clients be provided detailed information about their chosen method, and that clients receiving an experimental method or procedure be advised of potential risks and benefits and give informed consent. Legally requiring these safeguards had the desirable effect of focusing renewed attention on the issue of informed and voluntary decision making in FP programs. However, in EngenderHealth's view, the Tiahrt requirements are necessary, but not sufficient, to ensure truly informed and voluntary client decisions.

The principles of informed and voluntary decision making are not new in SRH. They have been fundamental tenets of quality FP services for decades. Over the last 20 years, much progress has been made in building a global consensus for principles of individual choice in FP, and large investments have been made to develop counseling training and services as the chief safeguards of informed choice in FP.

In addition, since 1994, population policies around the world have undergone a fundamental change as governments and donors embraced an expanded reproductive health framework and committed to supporting individuals' sexual and reproductive rights. In several international conventions and conference programs of action (including the International Conference on Population and Development [ICPD] in Cairo in 1994 and the Fourth World Conference on Women in Beijing in 1995), the international community affirmed that individuals have the right to make decisions concerning SRH free of discrimination, coercion, and violence. These affirmations extended the principles of informed and voluntary decision making beyond FP to the full array of SRH services.

Despite advances in support of informed and voluntary decision making in SRH, a wide gap still exists between the rhetoric and the reality at the service-delivery level. Barriers to informed and voluntary decision making persist for many reproductive health care clients worldwide as a result of social factors, laws, policies, service-delivery practices, resource constraints, and service providers' attitudes. These barriers will remain until policymakers, program managers, and service providers are better informed about clients' rights and what they mean in terms of service delivery, and until the implications of the broader social and cultural context for individuals' ability to obtain information, make decisions, and seek services are considered.

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\* Before March 2001, EngenderHealth was known as AVSC International.

Recognizing the gap between rhetoric and practice, and wanting to respond to the need to make informed and voluntary decision making a reality for more FP clients, EngenderHealth convened a group of international experts in 1998 to recommend new strategies. The experts recommended incorporating the rights and social context into approaches to informed choice in FP and moving toward a more client-centered service model that takes the client's comprehensive SRH needs into consideration. EngenderHealth addressed these recommendations by developing an expanded conceptual framework for informed and voluntary SRH decision making, which is the basis of this tool kit. This framework encompasses factors that extend beyond the clinic and applies to services beyond FP. It identifies the basic elements of informed and voluntary SRH decision making, as well as concrete indicators that one could look for to determine whether or not a specific element is in place. All of the requirements that the Tiahrt Amendment specifies are incorporated in this framework, but the framework takes an even more comprehensive view of the issue than the provisions of the amendment demand.

This tool kit was initially developed specifically for FP services. However, recognizing that clients have decisions to make about other SRH services and that some aspects of decision making are unique to specific services led us to identify the need for tool kit modules for other reproductive health services. The need for service-specific modules for STI/HIV and postabortion care (PAC) was reinforced by program staff in Ghana and Uganda during field testing of the FP module. EngenderHealth envisions developing a package of tool kit modules for a range of services in response to this need.

## Rights in Sexual and Reproductive Health Services

The Programme of Action crafted by the international community at ICPD in 1994 marked a fundamental shift from the long-standing demographic focus of population programs to a focus on health and human rights. The rights-based approach, as adopted at that conference, has been described as reflecting “a new global policy consensus on the relationships between population policy and sexual and reproductive rights: if women are empowered and people's needs for sexual and reproductive health are met, population stabilization will be achieved by virtue of choice and opportunity, not coercion and control.” \*

The rights-based approach to SRH assumes that health is a basic human right. Basic elements of this approach include “gender equity and equality, sexual and reproductive rights, and client-centered sexual and reproductive health care.”\* *Reproductive rights* refers to an individual's right to exercise control over his or her own body, sexuality, and reproduction. *Sexual and reproductive rights* have been variously defined to include:

- Gender equity
- The right to attain the highest standard of sexual and reproductive health
- The right to safety and dignity
- The right to decide whether and when to have children, and how many
- Rights to information about and access to a range of SRH services

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\* Family Care International. 2000. *Sexual and reproductive health briefing cards*. New York.

- The right to make decisions and to exercise control over one’s sexuality and reproduction free of discrimination, coercion, and violence
- The right to protect one’s health and to prevent disease
- The right to choose among available options
- The right to privacy and confidentiality

The essence of a rights-based approach to service delivery is helping individuals exercise the right to make and act on their own decisions about their health and reproduction. The challenge for service providers is to help clients access whatever information and services they need and to help them make the decisions necessary to achieve SRH and their desired family size.

While many governments and donors have formally committed to upholding these rights, the rhetoric has not become a reality in most parts of the world for many complex reasons. Individuals’ status (economic, education, gender, age, and marital) within their family and their culture influences their awareness of and ability to exercise their sexual and reproductive rights. Members of marginalized population groups, notably women and adolescents, are less able to assert their rights than more privileged and powerful members of their community. Cultural constraints on individuals’ ability to enjoy their sexual and reproductive rights will not be overcome unless and until social norms change.

In order for these rights to be “real” for individuals, they need to be defined and presented in ways that are culturally appropriate and meaningful in specific settings, and they need to be recognized and protected by law or policy. Individuals need to know that they have such rights and will be supported in exercising them. Service providers also need to understand sexual and reproductive rights, their role in supporting clients to exercise these rights, and the power imbalances inherent both in their culture and in the client-provider relationship, which can impede clients’ ability to assert their rights. Furthermore, the traditional “medical model” of service delivery, which persists in many places and focuses on medical considerations without addressing clients’ personal circumstances and preferences, needs to be transformed to more client-centered care.

Much of the language of sexual and reproductive rights focuses on the clients’ right to make decisions “freely and responsibly.” Thus, one of the most concrete ways in which we can support a rights-based approach to SRH is to support informed and voluntary decision making.

## Overview of Informed and Voluntary Decision Making

The international community has clearly stated and widely endorsed the rights of individuals to access SRH services, to make their own decisions about their SRH care, and to have the information necessary to make those decisions. Enabling clients to make informed and voluntary decisions regarding their SRH remains a challenge despite efforts to build a strong policy consensus for informed choice and voluntary decision making in FP, to train service providers in communication skills and counseling, and to require informed consent for specific methods and procedures. In recent years, the increased focus on clients’ rights and the expanded SRH agenda have added dimensions to the issue of SRH decision making that challenge service providers to try new approaches and adapt the FP model to a wider array of services.

*Informed choice* is defined as a voluntary, well-considered decision that an individual makes on the basis of options, information, and understanding. The concept most commonly applies to clients' FP choices. The concept of *informed and voluntary decision making* applies broadly to any health care decision and assumes that individuals have both the right and the ability to make their own health care decisions. Decision making about SRH is complex and individualized. It involves determining whether or not to seek services, when and where to do so, which treatment or services to select, whether or not to return for follow-up or referral, whether or not to comply with treatment or method instructions, and whether or not to continue, change, or discontinue a method or treatment altogether. These decisions are influenced by an interplay of factors related to individual circumstances; the legal, social, and rights context in which the individual lives; policies affecting information and services; and practices in service delivery.

Individuals obtain information about SRH from multiple sources. They may make their decisions alone or in consultation with family members, friends, or health care workers. Every encounter, both verbal and nonverbal, that an individual has with a health care worker is defined as a *client-provider interaction (CPI)*. *Counseling* is a specific form of CPI aimed at helping clients to confirm or reach informed and voluntary decisions about their health care and to understand the details of their chosen treatment or method. Service providers' ability to support clients in making decisions that reflect their needs is influenced not only by conditions within the service setting, but also by policies and factors in the society and community.

This tool kit addresses the continuum of the decision-making process that begins in the individual's home and community and includes the service-delivery experience. The tool kit is structured on the basis of an expanded conceptual framework that describes desirable elements and conditions that enable informed and voluntary SRH decision making, as well as factors that may support or hinder such decision making and need to be considered at several levels.

## An Expanded Conceptual Framework

The following basic elements or conditions support informed choice and voluntary SRH decision making:

1. Service options are available.
2. The decision-making process is voluntary.
3. Individuals have appropriate information.
4. Good client-provider interaction (CPI), including counseling, is ensured.
5. The social and rights context supports autonomous decision making.

For each of these elements or conditions, the framework suggests indicators that one can look for to assess whether or not these elements or conditions are in place. In an FP program that supports informed and voluntary decision making, one would expect to find that:

### 1. Service options are available.

- Family planning (FP) services are available where and when individuals need them.
- A choice of methods is offered.
- Options are affordable.

- Referral mechanisms are in place for other methods.
- Linkages exist with other health services.

## **2. The decision-making process is voluntary.**

- Individuals are free to decide whether or not to use services, without coercion or constraint.
- Clients are free to choose among available methods, without coercion or constraint.
- A range of service options is accessible to all categories of clients, including adolescents and unmarried individuals.
- Service providers are objective regarding all clients and methods.
- The individual's right to choose is respected and supported.

## **3. Individuals have appropriate information.**

- Individuals have access to appropriate and accurate information about services and options.
- Individuals understand their risk for STI/HIV/AIDS and the protection that FP method options provide.
- Service providers assess clients' knowledge, fill any gaps, and correct any misinformation.
- Comprehensible posters and flipcharts are clearly in clients' view.
- Samples of FP methods are available for clients to see and touch.
- Clients understand their options, the essential information about their chosen method or treatment (including benefits and risks, conditions that would render it inadvisable for use, and common side effects),\* and the way their choice may affect their personal circumstances.

## **4. Good client-provider interaction (CPI), including counseling, is ensured.**

- Clients and service providers have dynamic, two-way interaction.
- Clients actively participate in discussions and are encouraged to ask questions.
- Staff have good communication skills (talking, listening, eliciting, probing, assessing).
- Counseling staff provide individualized care, tailoring the client-provider interaction (CPI) and information to what clients want and need, and addressing individual circumstances and concerns.
- All staff use language and terms that clients can understand.
- Counseling staff have complete and correct information about SRH and available services.
- Staff answer clients' questions fully and clearly.
- All staff are empathetic, respectful, nonjudgmental, and sensitive to power imbalances and gender differences between clients and providers.
- All staff maintain clients' privacy and confidentiality.
- Trained staff are assigned to counsel clients as a routine component of service delivery.
- Counseling serves as the checkpoint to ensure informed and voluntary decision making.
- Memory aids are used by staff and provided to clients.
- The service setting is organized, clean, and cheerful to put clients at ease.
- Auditory and visual privacy are ensured for counseling, regardless of the setting.
- Adequate seating is available during counseling for counselors, clients, and anyone else the clients choose.

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\* Tiahrt Amendment, 1998.

## 5. The social and rights context supports autonomous decision making.

- Laws, policies, and social norms support the following:
  - ▼ Gender equity
  - ▼ Individuals' rights to decide whether and when to have children, and how many\*
  - ▼ Clients' right to access SRH information and services regardless of age, sex, marital status, or sexual orientation\*
  - ▼ Clients' right to make decisions and to exercise control over their sexuality and reproduction free of discrimination, coercion, and violence
  - ▼ Clients' right to protect their health and prevent disease
  - ▼ Clients' right to privacy, confidentiality, dignity, and safety

## Three Levels to Consider and Discuss

Multiple factors within and beyond the service setting affect clients' ability to make informed and voluntary SRH decisions. This tool kit facilitates consideration of such factors at three levels:

- Individual/community factors
- Service-delivery factors
- Policies

**Individual/community factors** include all of the family, educational, religious, and social norms that individuals experience living in a particular community, as well as the unique ways that individuals process and interpret all of these factors. An individual's sense of what he or she needs and wants in terms of his or her own SRH is a very personal experience that is heavily influenced by community values and expectations. These influences are particularly powerful in determining desired family size, sexual behaviors, whether or not to seek health care and ways to do so, FP method preferences, and what topics individuals feel that they can or cannot talk about, and with whom. Such communication opportunities and/or constraints are key to the "informed" element of informed and voluntary decision making. The community also plays a powerful role in determining who is expected, or allowed, to make decisions about SRH, as well as which kind of decisions are acceptable. Both of these elements have a direct bearing on the voluntary nature of decisions.

**Service-delivery factors** describe what actually exists and happens in practice, regardless of what is supposed to happen according to policy. Factors at this level that influence client decision making include the service options offered; the availability of trained personnel; service providers' skills, attitudes, and comfort in addressing SRH issues; the organization of services; and supervisor and management support for client-centered care. Service providers' awareness of their clients' rights and circumstances, and of the power imbalances between them and their clients, has a direct bearing on the quality of CPI and on SRH decision making. Similarly, service providers' self-awareness regarding their own values, and the recognition that they themselves are subject to the social and cultural context in which they live and provide services, are important factors that influence whether or not they support clients' right to make informed and voluntary decisions.

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\* ICPD Programme of Action, 1994.

**Policies** can include international conventions (e.g., the ICPD Programme of Action), donor requirements (e.g., the Tiahrt Amendment), government policies, laws, rules, regulations, program goals, protocols, and service-delivery guidelines. Policies are influenced by politics, economics, demographic pressures, religion, cultural expectations, and public opinion. Some policies foster a supportive environment for client-centered care, sexual and reproductive rights, autonomous decision making in SRH, and informed choice for FP services. Others limit access to information or services, thus hindering individuals' ability to make informed and voluntary decisions. Policies related to service programs are meant to guide program managers and service providers by clarifying roles, responsibilities, and performance expectations. Sometimes good policies exist but are not implemented in practice because of inadequate dissemination, misunderstanding or poor communication, or constraints that impede staff from putting policies into effect as intended.

## Potential Audiences and Uses of This Tool Kit

This tool kit has been designed for use by a wide range of audiences in different settings for multiple purposes. Potential users include:

- Policymakers
- Donors
- Managers of service programs
- Managers of community-based organizations
- Members of community groups
- Trainers
- Service providers
- Staff of technical assistance agencies

The goal of this tool kit is to help users support individuals in making informed and voluntary decisions about their SRH. Its purposes are to help them:

- Understand key concepts of informed and voluntary decision making in SRH care
- Identify and consider factors that affect informed and voluntary decision making on the individual/community, service-delivery, and policy levels
- Identify which of those factors are challenges to informed and voluntary decision making and which ones are supportive
- Develop strategies and action plans to address challenges and strengthen support for clients' informed and voluntary SRH decision making in service delivery
- Monitor and assess program quality and progress
- Develop baseline study instruments

The following examples illustrate how the tool kit may be used by different audiences:

- **Donors who support SRH programs and international technical assistance agencies** may use it as a planning tool to identify key strategies for supporting informed and voluntary decision making, and for increasing awareness of informed choice as one of the key rights of individuals and as a key element of quality of care.

- **Policymakers or managers** may use it to identify strengths and weaknesses of their programs with respect to client-centered care and to formulate strategies and safeguards to support SRH decision making in service programs.
- **SRH program managers** may use it as a training tool for service providers and other staff to increase awareness of and support for clients' right to make informed and voluntary decisions, and to identify ways to better meet clients' needs in this area.
- **Community groups** may use it to guide public discussions, with the goals of clarifying needs and concerns about SRH service delivery and/or increasing awareness and support for individuals making informed and voluntary decisions in the context of SRH.
- **Coalitions representing all of these groups** may use it to help bridge the differences in approach and perspective among groups, to learn from each other, and to foster cooperation and coordination in planning and implementing strategies to support informed and voluntary SRH decision making.

## Guide to Using This Tool Kit

This tool kit consists of four sections:

- Introduction
- Discussion Guide
- Preliminary Assessment Guide
- Next Steps Guide

It is designed to be used with the guidance of a facilitator who has in-depth knowledge of informed and voluntary SRH decision making.

Depending upon the objectives of the exercise, the tools in the kit can be used separately or together in a series of steps, as follows:

- a. Discussion Guide:** This tool is intended to be used to facilitate a broad discussion of the elements and conditions that underpin the concept of informed and voluntary decision making, as well as indicators to look for that determine whether or not these elements and conditions are in place.

This guide can be used in orientations and trainings to increase participants' understanding of key concepts and expand the thinking beyond service delivery to include social, cultural, rights, and policy factors. It can also be used in conjunction with the Preliminary Assessment Guide (described below) to trigger ideas regarding factors that affect informed and voluntary SRH decisions in specific settings.

- b. Preliminary Assessment Guide:** This tool is intended to help users assess the status of SRH decision making in a given program by identifying the challenges and supporting factors at the individual/community, service-delivery, and policy levels. It is most effectively used in conjunction with the Discussion Guide. To complete the preliminary assessment, users should be guided to identify factors at the three levels that have a direct bearing on SRH decision making and to determine whether each factor constitutes a challenge, a support, or an important consideration for clients' SRH decision making in their particular setting. (See page 11 for an explanation of "consideration.")

Referring to the Discussion Guide while completing the Preliminary Assessment Guide helps prompt users to think about relevant factors and may trigger other ideas. The result will be a snapshot of the status of SRH decision making in a particular setting that recognizes program strengths and targets factors at different levels that need to be addressed to strengthen informed and voluntary SRH decision making.

Users can apply the findings of the preliminary assessment to guide the development of strategies to support client decision making in SRH programs. They can also use the findings to help formulate evaluation indicators, produce more specific needs-assessment instruments, or guide the design of in-depth studies. In addition, the supportive factors identified at the service-delivery level can provide a basis for clarifying performance expectations and developing a performance-appraisal instrument.

**c. Next Steps Guide:** This tool is intended to help users plan strategies to strengthen supports for clients' SRH decision making. Having identified challenges, important considerations, and supporting factors specific to their community or program, users should be guided to think about what they can do to strengthen each of the five desired elements or conditions of the SRH decision-making framework. When considering action steps and strategies to address the challenges and bolster or introduce supports, users should think about key stakeholders, possible roles and responsibilities, available and potential resources, priorities, and a timeframe.

The action plan resulting from the Next Steps Guide can serve as the basis for developing a detailed strategy and activity plan that can be implemented, monitored, and evaluated for its impact on SRH decision making in service delivery.

## Notes for Facilitators

This tool kit is intended to be used by groups in a facilitated process. The group should include a mix of individuals who represent the individual/community, service-delivery, and policy perspectives. The facilitator or facilitators should be well versed in informed and voluntary SRH decision making and family planning. It would be helpful if they have an awareness of the individual/community, service-delivery, and policy context of the program under discussion as well.

### *Small-group work*

Field tests have demonstrated that a variety of approaches to using this tool kit can be effective in various settings. When the group contains fewer than 10 participants, the entire group can be involved in all discussions. When facilitators work with large, diverse groups, different aspects of the Discussion Guide and Preliminary Assessment Guide can be assigned to subgroups. The participants can then share their findings in plenary, followed by a full-group discussion of next steps for maximum involvement, ownership, and commitment.

For example, in some settings, participants have been divided into three small groups. One group was assigned to discuss and fill in the Preliminary Assessment sheet for the individual/community factors for all five elements (see pages 35, 37, 39, 41, and 45), another group was assigned to do the same for the service-delivery factors, and a third group did the same for the policy factors. When the groups shared

their conclusions in plenary, a copy of the Preliminary Assessment Guide was drawn on a flipchart and completed in front of the entire group, covering one element at a time. As each group (individual/community, service-delivery, and policy) reported its conclusions, the facilitator pointed out common themes and differences among the three groups. For example, in one workshop, all small groups shared the observation that good policies regarding informed and voluntary decision making, client-centered care, and clients' rights exist, but that there is little awareness of these policies at the service-delivery level. (In this case, one of the "next steps" that the groups identified was to do a better job of disseminating policy documents and explaining their implications, both at the service-delivery and the community levels.)

Another approach that has worked effectively in larger groups is to divide the participants into five small groups and have each one consider factors at all three levels for just one element or condition. A third variation has worked well in a larger group representing different programs or geographic districts. Dividing the larger group into small groups along the natural lines of program or geography fosters assessment and planning at a realistic operational level. As above, each small group then reports back to the other groups for a broad discussion of all elements and conditions with the larger group.

It is desirable to involve as many stakeholders as possible in recommending next steps and developing strategies and objectives using the Next Steps Guide. Being inclusive yields the benefits of multiple perspectives; buy-in from different levels of staff, policymakers, and community groups; and pooled resources.

### ***The difference between "What to strive for" and "What to consider and discuss" in the Discussion Guide***

The bullets under "What to strive for" describe what one would like to see in place under the ideal condition of informed and voluntary decision making. They are all positive statements. The purpose is to give participants a concrete sense of what factors contribute to and support informed and voluntary client decisions (i.e., "What does it look like?").

The bullets under "What to consider and discuss," on the other hand, are neutral statements about factors for participants to consider. It is for them to determine whether the factors constitute a challenge, an important consideration, or a support for SRH decision making in their particular program or context (see the Preliminary Assessment Guide on page 33). These bullets cover important issues that can influence, either positively or negatively, individuals' access to information and services and how they make decisions. In some instances, the same factor could be either a challenge or a support depending on whether it is absent or present. Also, what may be a challenge or important consideration in one setting could be considered a support in another, particularly from the community perspective.

The bullets under "What to consider and discuss" are meant to cover a broad range of issues, but the lists are not necessarily complete. They should act as triggers to spark discussion. Not all the bullets will apply to all situations, and additional important issues related to the local program or environment may need to be considered.

### ***Helping participants determine “Challenges/Considerations” and “Supports” using the Preliminary Assessment Guide***

Keeping the bullets neutral under “What to consider and discuss” requires the facilitator to play an active role in helping participants think through the status of factors in the given program or setting, as well as to decide whether and how each applies to their situation, either supporting or challenging informed and voluntary decision making. “Considerations” are significant factors that may not specifically help or hinder but warrant participants’ attention.

The facilitator should guide the group to consider each factor in order to describe whether and how it applies in their program, giving it a positive or negative value. To do this, the facilitator needs to direct the participants and ask probing questions to help them think through the ideas. For example, the facilitator might ask, “Does this factor exist in your situation? Does it support or challenge informed decision making? Voluntary decision making? In what way?”

Note that the preliminary assessment and the development of the action plan can be carried out and recorded on a flipchart by following the formats provided in the Preliminary Assessment Guide and the Next Steps Guide.

A few examples of “Challenges/Considerations” and “Supports” for the first element are provided on the next page.

## *Examples of Challenges/Considerations and Supports*

### **Family Planning: Preliminary Assessment Guide**

#### **1. Service Options Are Available.**

##### **What to strive for** .....

- Family planning (FP) services are available where and when individuals need them.
- A choice of methods is offered.
- Options are affordable.
- Referral mechanisms are in place for other methods.
- Linkages exist with other health services.

#### **Individual/Community Factors**

<b>Challenges/Considerations</b>	<b>Supports</b>
<ul style="list-style-type: none"><li>■ The community has not made sexual and reproductive health (SRH) a priority; demand for services is low.</li><li>■ Because of poor roads and high transportation costs, access to services and method choices is limited.</li></ul>	<ul style="list-style-type: none"><li>■ Community-development groups help to identify health care needs and priorities and communicate them to decision makers.</li><li>■ Clinics are conveniently located.</li></ul>

## Service-Delivery Factors

Challenges/Considerations	Supports
<ul style="list-style-type: none"> <li>■ All methods are available in principle, but some methods are available only on certain days; stock-outs are common.</li> <li>■ Service providers are not trained to offer all methods that should be available.</li> </ul>	<ul style="list-style-type: none"> <li>■ Service providers are adequately trained to offer all methods at all times.</li> <li>■ Service providers are trained to identify other SRH needs of FP clients; there is an established referral network linking SRH services.</li> </ul>

## Policies

Challenges/Considerations	Supports
<ul style="list-style-type: none"> <li>■ The program relies heavily on “camp” sterilization services to meet the needs of individuals living in remote areas, offering limited method choice.</li> <li>■ Health-sector reform has reduced access to FP services.</li> </ul>	<ul style="list-style-type: none"> <li>■ Policies to provide a range of methods are in place.</li> <li>■ A policy initiative to integrate FP and SRH services has resulted in better staff orientation and linkages among services.</li> </ul>

