Sexual and Reproductive Health Needs of Women and Adolescent Girls living with HIV

Research Report on Qualitative Findings from Brazil, Ethiopia and the Ukraine

July 2006

EngenderHealth/UNFPA

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Acknowledgements

UNFPA and EngenderHealth would like to acknowledge the invaluable support of those who contributed to this qualitative study and report.

The HIV-positive women and adolescent girls and male partners of HIV-positive women, who so giving of themselves, found the time to generously share their experiences and stories in the name of improving services for other women and their community. The health workers, programme managers, policy makers, and community leaders who agreed to be interviewed for this research and who wholeheartedly spoke about their experiences for the aim of improving services for women in their communities.

The principal investigators for the study, Rasha Dabash and Paul Perchal.
The principal writer Rasha Dabash and reviewers Marcia Mayfield, Paul Perchal and Lynn Collins.

The research teams and Ministries of Health in Brazil, Ethiopia, and the Ukraine including Beyeberu Assefa, Silvani Arruda, Oksana Babenko, and Sharone Beatty. The PLWH organizations that assisted with recruiting research subjects for the study including Positive Prevention Group and the National PLWH Network of Brazil (Brazil), Mikdam (Ethiopia), and Club Svitanok (The Ukraine).

UNFPA and EngenderHealth colleagues both at the country level and in New York for their ongoing support and inspiration.

These activities and report were made possible through financial support from UNFPA. The views and opinions expressed in this publication are those of the authors and do not necessarily reflect those of UNFPA, the United Nations Population Fund.

EXECUTIVE SUMMARY

Globally, women represent almost half of the 40 million people worldwide living with HIV and are increasingly becoming a larger proportion. Many women who are HIV positive do not know their HIV status until they become pregnant and are tested as a part of antenatal care. For many HIV positive women, antenatal care and PMTCT are the primary entry points to SRH services as HIV positive women. This presents an opportunity for counselling and access to services to address future SRH needs. For women living with HIV, the challenges of receiving adequate SRH services are often complicated by stigma and discrimination resulting in denial of their rights under the guise of preserving health or preventing perinatal transmission. Limited access to other health services, including care and treatment, also has dire consequences on HIV positive women's ability to protect their health, placing this already vulnerable population at even greater risk of morbidity and mortality.

Between January and July 2005, research teams in Brazil, Ethiopia and the Ukraine carried out a total of 11 focus group discussions and 93 in-depth interviews. In all, the research included 182 respondents, including women and adolescent girls living with HIV, male partners of women living with HIV, providers, and policy influentials[1]. The research explored the sexual and reproductive health intentions and needs of individuals and probed issues relating to family planning, sexually transmitted infections, breast and cervical cancer, maternity care services and the prevention of mother-to-child transmission as well as access and quality of care.

Key Findings

This research identified some interesting trends across the three countries and some issues unique to each setting that need to be considered in strategic planning efforts to improve HIV-positive women's and adolescent girl's access and utilization of SRH services. Research findings suggest that women and adolescents living with HIV face many challenges to exercising their rights. Limited access to information, counselling and services, poor quality or insufficient care, stigma and discrimination, gender inequalities, and often faltering community and family support are among the barriers which confront HIV positive women and adolescents.

The provision of effective reproductive health care for HIV positive women should be guided first and foremost by a rights-based approach. Policies and programmes should address identified gaps through advocacy, strategic planning, and collaborative international and local commitment to bridging the reality of existing services and women's desires and rights to fulfilling lives that include making informed choices about their sexual and reproductive

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[1] Policy makers and community leaders

health.

This research indicates more advocacy is required, including engagement of policy influentials, to address lack of awareness, and policy and programmatic gaps, regarding the rights and health needs of HIV-positive women and adolescent girls. There is unevenness of health providers' understanding of SRH of women living with HIV and an inability to respond to their rights. It is also essential to ensure that HIV-positive women and adolescent girls are aware of their rights so they can exercise them.

Recommendations for Further Research

The findings from this study suggest a number of issues or areas for further research including:

- Operations research to address the various programmatic and policy gaps highlighted in this report, such as testing ways to improve access to and quality of SRH services for HIV-positive women and adolescent girls; approaches for reducing stigma and discrimination; and models of service delivery that link SRH and HIV programmes through integrated approaches.
- Exploring approaches to making PMTCT services more widely available by integrating PMTCT into health services in rural areas and outside of specialty research centres in urban areas.
- Assessing missed opportunities for meeting women's SRH needs within the context of existing services in order to understand the root causes of service gaps, including replication of qualitative studies similar to this one in other settings.
- Conducting research similar to the current study in rural areas may yield different results and raise additional issues since most of the respondents in this study were based in primarily urban regions.
- Additional research is needed to clarify issues around hormonal contraceptive use by HIV-positive women, as current gaps in the science make providers more likely to promote only condoms.
- Investigating ways that providers, social workers, peer educators, and others working with HIV-positive women and adolescent girls can help them develop the necessary skills to negotiate condom use.
- Exploring ways to make the voices of HIV-positive women and adolescent girls, as well as their advocates (e.g. health providers, feminists, PLWH groups), heard on the issue of rights and needs of HIV-positive women.

Conclusions

This qualitative study will contribute to a rights-based framework on policy, health systems, and advocacy guidance on SRH for PLWH, especially women and adolescent girls currently under development with key partners. SRH services for PLWH must be accessible, non-discriminatory, compassionate, of high quality and rights-based.

I. INTRODUCTION

A. Background

Globally, women represent almost half of the 40 million people worldwide living with HIV. Due to women's greater physiological, socio-cultural and economic susceptibility to HIV infection, it is likely that the proportion of female adults and young women living with HIV will continue to rise in many regions of the world as has already been seen in Sub-Saharan Africa and the Caribbean.[2]

Despite the growing magnitude of the HIV pandemic, health interventions that focus on providing care and treatment for HIV-positive individuals have come at a slow pace. Most women do not know their HIV status until they become pregnant and are tested as a part of antenatal care. Due to antenatal care, more women than ever are accessing voluntary HIV counselling and testing (VCT) and prevention of mother to child transmission (PMTCT) programmes in many developing countries, however the breadth and quality of services provided to HIV-positive women are still inadequate. Often lacking are services linking women to appropriate care and treatment, including anti-retroviral (ARV) treatment and comprehensive sexual and reproductive health (SRH) services that can allow women to maintain control over their lives and exercise their rights.

Through lack of access and stigma and discrimination, HIV-positive women and adolescent girls are often denied their rights. In the absence of informed choice and adequate reproductive health services (including care and treatment for reproductive morbidities that may be exacerbated by their HIV infection) HIV-positive women are at even greater risk of morbidity and mortality. They are a group whose needs are complicated by the enormous social stigma and discrimination associated with living with HIV.

To date, little research has focused on exploring the barriers of care and comprehensive SRH services for this group. To better understand how policies and programmes can best respond to the SRH needs of HIV-positive women and adolescent girls, EngenderHealth carried out qualitative research in Brazil, Ethiopia, and the Ukraine as part of a more comprehensive effort to advocate for rights and their SRH needs The research aims to understand the knowledge and perception of SRH needs of HIV-positive women and adolescent girls from the perspective of a wide group of stakeholders and to identify areas for further research.

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[2] UNAIDS/WHO: AIDS Epidemic Update 2005.

B. Purpose of the Research

The research is part of a larger collaborative project between EngenderHealth, UNFPA, International Community of Women Living with HIV/AIDS (ICW) and other key partners to develop a policy and programme framework and implementation package to address the SRH needs of HIV-positive women and adolescent girls. The specific objectives of the research are to:

- Identify the perspectives of HIV-positive women and adolescents, male partners of HIV-positive women, providers and policy influentials about SRH needs of HIV-positive women and adolescent girls.
- Determine barriers and facilitating factors to SRH services in different settings for HIV-positive women and adolescent girls.
- Guide the development of the SRH framework that addresses the needs of HIV-positive women and adolescent girls by suggesting potential policy and programmatic actions to consider.

Using qualitative methods, the study sought to identify and understand the needs, gaps and barriers to access and use from the perspectives of stakeholders using qualitative methods. Qualitative methods were selected due to their flexibility and ability to explore newer issues from the vantage point of respondents, while allowing for broad insight into the range of issues involved.

II. METHODOLOGY

A. RESEARCH SITES

The research was conducted in Brazil, Ethiopia, and the Ukraine. The selection of the geographic regions and respective research sites where the study was conducted was the output of a collaborative process based on the input of local research partners, Ministry of Health staff, networks of people living with HIV (PLWH), UNFPA, and EngenderHealth. Several factors were considered as criteria for selecting research areas, including high HIV prevalence, availability and range of SRH services, strong relationships between local partners and strong political will and impetus to incorporate the findings of the framework and its interventions. The presence of PLWH networks was also a key factor as was the capacity to mobilize to conduct the research in a timely manner.

In the Ukraine and Ethiopia, the research built on another collaborative EngenderHealth and UNFPA project designed to strengthen HIV aspects of SRH services. Hence the research was conducted in the sites surrounding the health facilities participating in that project and was limited to one geographic region in each country. The main catchments for research were the Donetsk region of the Ukraine and Addis Ababa and the surrounding vicinity in Ethiopia. In Brazil, the research included the perspective of stakeholders from multiple cities, including Brasilia, Sao Paolo, Recife, and Rio de Janeiro.

Many factors influencing the SRH needs, such as the epidemiology and magnitude of HIV infection, political will, access to services, and socio-cultural norms vary between and within these three settings (see Table 1, page 9). As such, the approach to how the research was carried out was adapted to each setting, keeping in mind the geographic region where the framework and its proposed elements would be tested and implemented.

Table 1: Overview of the AIDS Epidemic in Study Countries

	HIV Prevalence Rate (15-49 yrs)	Estimated Number Living with HIV/AIDS	Women and HIV	Anti-Retroviral Therapy Availability
BRAZIL[3]	0.7%	660,000	Women represent 36 % of those living with HIV/AIDS.	Estimated 80% treatment coverage.[1] Since 1996, government began offering universal and free access to antiretroviral. Today, about 160,000 individuals receive such treatment through the public health system.[5] Brazil distributes 17 anti-AIDS drugs, including eight generic versions and nine imported brands, free of charge.
ETHIOPIA[4]	4.4%	1,500,000	Women represent the majority of new HIV/AIDS cases. HIV prevalence higher among women than men (5% compared to 3.8%). In antenatal clinics 8.2 % prevalence.	Some limited access, mostly in large urban centres. Estimated 245,000 persons in need of ART. Currently, AIDS accounts for estimated 30% of deaths among young adults.
UKRAINE[5]	1.4%	590,000	Women represent 40% of those infected with HIV/AIDS. Injection drug use remains the main route of transmission; however heterosexual infection has grown from 5.3% to 20% between 2001 and 2003.	Limited availability. Estimated that only 11% of those requiring treatment receive it.[6]

B. RESEARCH DESIGN AND IMPLEMENTATION

Research instruments were developed based on key SRH areas to be addressed in the broader framework of rights and SRH services for HIV-positive women and adolescents. Research probes were also guided by key themes from UNFPA/WHO's draft clinical guidelines on SRH services for women living with HIV.[7]

Research instruments were respondent-group specific. The instruments were designed to be open-ended and to include probes for potential additional issues (see Appendix 1) that could emerge as important concerns among the

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[3] International AIDS Society: HIV/AIDS Fact Sheet in Brazil and Latin America. www.ias.org

[4] Ethiopia Federal Ministry of Health, Disease Prevention and Control Department. AIDS in Ethiopia. Fifth Report ;June 2004.

[5] Avert: HIV/AIDS in Russia, Eastern Europe & Central Asia. www.avert.org.

[6] World Health Organisation. Progress on global access to HIV antiretroviral therapy: and update on 3 by 5. 2005.

[7] UNFPA/World Health Organization 2006, Sexual and Reproductive Health of Women Living with HIV: Guidelines on care, treatment and support for women living with HIV/AIDS and their children in resource-constrained settings.

various respondent groups. All instruments were designed in English then translated into Portuguese, Russian and Amharic.

To refine language and adapt questions to respondent needs, translated instruments and informed consent forms were pre-tested with a small sample of individuals from each respondent group in each country. Based on pre-test findings, minor adjustments to question were made in some settings. Pre-test allowed the research teams to gain practice using the study tools; findings from the pre-tests were not included in the overall study findings.

The research protocol and tools, including informed consent forms, in-depth interviews (IDI) and focus group discussion (FGD) guides were submitted for ethical review according to EngenderHealth's research guidelines. An additional similar submission process was carried out in Brazil prior to the start of any interviews or discussions. In-country ethical review was not required in Ethiopia and the Ukraine.

Significant input on the research design, sampling and implementation, as well as feedback on the analysis, was provide by the 3-5 person country research team that was led by a local coordinator and included at least one person from the local PLWH network.

Local research teams had varying experience with HIV/AIDS issues and research. All team members participated in an in-country orientation on the research aims and design as well as training on qualitative research methods and research tools. Almost all provider and policy-influential interviews were conducted by the local research coordinators, while FGDs and IDIs with HIV-positive women and male partners of HIV-positive women were led by same gender researchers from the team.

C. SAMPLING

A total of 11 focus group discussions and 93 in-depth interviews were conducted with research respondents (n=182), including HIV-positive women and adolescents, male partners of HIV-positive women, providers, and policy influentials (Table 2). All provider and policy-influential data were collected by IDIs. FGDs with HIV-positive women were carried out in Brazil and Ethiopia and were stratified by age as noted in Table 2. In Brazil, adolescents age 15-19 participated in one FGD, however no adolescents were interviewed in the other 2 countries due to local restrictions regarding minimum age of consent for research in The Ukraine and Ethiopia. In The Ukraine all research, including research with HIV-positive women and male partners used IDIs due to concerns about issues of confidentiality and stigma associated with group research.

Interviewed providers were from public health facilities and were primarily doctors and nurses. In Ethiopia and the Ukraine, they came from the sites participating in the collaborative EngenderHealth and UNFPA project to strengthen SRH services for HIV-positive women and adolescents. In Brazil they were from public health facilities in Brasilia, Sao Paolo, Recife, and Rio de Janeiro. Policy influentials included MOH officials, community leaders, social services department officials, and PLWH group leaders, among others.

Table 2: Sampling by Country and by Respondent Category

	Brazil(SãoPaulo, Brasilia, Rio de Janeiro, Recife)	**Ethiopia (Addis Ababa)**	**Ukraine (Donetsk)**	**All**
Adolescents(15-19)	8 (1 FGD)	Not included	Not included	8
Women(18-24yrs)	-	13 (2 FDGs)	4 (IDIs)	17
Women (25-45 yrs)	-	15 (2FGDs)	12 (IDIs)	27
Women (22-45 yrs)	32(3 FGDs)	-	-	32
Total HIV-positive Women	40 (4 FGDs)	28 (4 FGDs)	16 (IDIs)	84
Male Partners	8 (1FGD)	13 (2 FGDs)	7 (IDIs)	28
Providers	16 (IDIs)	13 (IDIs)	9 (IDIs)	38
Policy influentials	12(IDIs)	9 (IDIs)	11 (IDIs)	32
TOTAL RESPONDENTS	**76**	**63**	**43**	**182**

D. DATA COLLECTION

Data collection activities were carried out between January 2005 and July 2005. The country teams were responsible for all data collection activities with supervision provided by the local coordinator as well as the project manager and research consultant.

Based on the initial sampling list, policy influentials and providers were contacted for interviews. Few individuals refused interviews once the purpose of the research was explained. Some however, were not available during the research period or were only able to participate in a short interview due to interruptions. Verbal informed consent, including participant’s rights and information about the research were provided prior to all interviews as was permission to tape-record the confidential interview. On average IDIs with policy influentials and providers lasted one hour.

HIV-positive women were identified by PLWH networks in the three countries and in multiple settings in the case of Brazil. With the exception of The Ukraine where all persons were provided with informed consent information prior to the IDI, all HIV-positive women, adolescents and male partners of HIV-positive women in Brazil and Ethiopia received informed consent information in advance of FGDs as well as at the beginning of the FGD discussions. Focus group discussions lasted approximately 1.5 hours.

Select socio-demographic data were collected on all respondents, including age and gender. Additional information such as number of living children, educational level and partner's HIV status were also collected from HIV-positive women and adolescents and male partners of HIV-positive women, albeit not consistently in some settings due to confidentiality concerns by some participants. Socio-demographic data were linked to responses from audio tapes using a coding system, eliminating the use of individual names as a measure of confidentiality protection. All FGD and IDI tapes were coded numerically and then simultaneously translated and transcribed verbatim into English by a professional translator or service. A random sample of transcripts were reviewed and compared to the original tape by the in country research coordinator to verify accuracy. Minor issues of translation and terminology were also identified and corrected during analysis.

Research participants received no compensation for their participation in the study. For some community level participants, transportation costs were offered to cover their travel to the designated research site. Refreshments were also offered during the session. No compensation was provided to providers or policy influentials.

E. DATA ANALYSIS

Data analysis was carried out by the research consultant using the English transcripts and research team notes from the 3 countries and with the help of *Atlas.ti* software[8] for data coding, sorting and management. Analysis relied on a modified grounded theory approach[9] to explore existing themes and patterns that emerge from the data and to complement initial categories generated for coding. Analysis was carried out by country; however, due to overlap in themes and codes, data could also be sorted to reflect similarities and differences among countries. Key findings were generated for each country and provided to the country research teams for feedback and discussion. Study findings presented in this report are a summary of the key issues that emerged from the research.

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[8] Atlas.ti Software 2004. www.atlasti.org

[9] Strauss A, Corbin J: Basics of Qualitative Research: Grounded Theory Procedures and Techniques. 1990.

III. STUDY FINDINGS

A. INTRODUCTION

Key research findings presented below provide a summary of the perceptions of both the quality of existing SRH services for HIV-positive women and adolescents as well as the needs for improvements. Data are presented from multiple respondent perspectives, including those of HIV-positive women, male partners of HIV-positive women, health service providers and policy influentials. Throughout the findings section, raw data in the form of quotations from various respondents are provided to support the summary of study findings and allow for direct use of respondent's voices and ideas in the results. Findings are presented for each country by relationship to broad categorical topics such as perceptions of existing services, quality of family planning services, programmatic and policy priorities, etc. To the extent possible, the different perspectives within and among respondent groups are also compared and contrasted to demonstrate the range of views about the issues explored in the study.

B. KEY FINDINGS: BRAZIL

Sexual and Reproductive Health Intentions and Reproductive Rights: When asked who generally makes decisions about family size and other reproduction concerns in the context of Brazilian society, most respondents, including women, male partners, providers and policy influentials said that it was predominantly the women or the couple. Some respondents across all groups reported that while partners shared in SRH decisions, that due to gender power dynamics in many couples, men's influence and desires often dominated sexual relations and choice about fertility.

Women, adolescents, and male partners gave a wide range of responses as to the ideal number of children, ranging from 2 to 12. Many stated that 2 children, with one child of each gender were ideal, whereas some had no preference of gender. All respondents reported desired fertility became secondary when it came to couples where at least one partner is sero-positive because compromises need to be made to avoid or limit childbearing. Many said that they were content with whatever number of children they had once they found out they were HIV positive. Stigma associated with being an HIV-positive parent, the risks of vertical transmission, uncertainty about one's own health, and economic reasons were the most common reasons cited for avoidance of childbearing and there were mixed views about whether couples where one or both partners are HIV-positive should have children.

Men and women also reported that generally while providers were tolerant of HIV-positive women who accessed services while pregnant, they did not embrace the reproductive rights of these women, including the right to fertility.

Those who wished to get pregnant rarely shared their reproductive intentions with providers. HIV-positive women and adolescent girls also reported that they rarely received counselling that included information about their fertility options unless they were already pregnant. Many felt that providers were hesitant to give the information as to not encourage women to become pregnant.

> “Doctors have a lot of prejudices against us who are HIV+. It's just say we want to be a mother again that they say we're crazy and we'll put another sick child in the world to be orphan and suffer. And nowadays we know it's not like that anymore. That there's a chance, thanks God, of the child being born negative. And they are taking our right of being a mother away just because we're HIV+. Doctors say right away this is wrong and we should give up. As if we lost the right of be a mother which is a beautiful right God gave us. We're not different.” – 34 year woman, Recife, 4 children). [P31: bra.com.fgd.women22-44.recife.tape34+35.txt R#8 (34 IP 4)]

> “I think that the doctors who care for HIV+ women do whatever they can do to make sure that they do not have babies. They do what they can to make them afraid, to make them insecure. They convince women they cannot get pregnant under any circumstance. Many times they don't even give information about what could be done in case of pregnancy.” –44 year old HIV-positive women, IP, 1 child [P 6: bra.com.fgd.women22-44.tape8+9.txt R#2 (44 P 1)]

Responses of most providers and policy-influential suggested that while there was theoretical broad support for HIV-positive women’s reproductive rights in general, there were particularly mixed views when it came to HIV-positive women becoming pregnant. Some providers and policy-influential recognized how this limited women’s ability to make informed choices.

> “There is still much apprehension from our side to encourage those women to get pregnant and perhaps give birth to infected babies. I think that this can become a very serious health problem for the country and the world. So my point of view is that we need to further researches and try to have more safety before encouraging those women to get pregnant.”—provider São Paulo [P30: bra.pro.idi.SP.tape33.txt]

> “I think that a woman who says she wants to get pregnant is in the first place a rare bird, for what usually happens in public health is that either women arrive already pregnant or they don't talk to doctors about that at all before getting pregnant because they know they'll have a “NO” answer.”—Provider, Sao Paulo [P26: bra.pro.idi.SP.tape29.txt]

> “Most people do not think that adolescents have the right to be a mother, if they are HIV positive, it's much worse! Nowadays, pregnancy during adolescence is dealt with in any news programme on TV as if it were an epidemic.” —Provider Rio [bra.pro.idi.RdJ.tape17.txt]

> “To speak of rights doesn't mean to agree or disagree with the women on their choices, it means to support whatever choice they might make and to offer the mechanisms that guarantee their having access to what they choose.”-—Provider, Sao Paulo [P26: bra.pro.idi.SP.tape29.txt]

A few providers and policy influentials attributed the desire of HIV-positive women and particularly adolescents to get pregnant not only to their means to fulfilling a desire for children but an attempt to regain value and rights as a mother. It was suggested that this may be the outcome of a system that had not put enough emphasis into providing women who are not pregnant with the same quality SRH services available within PMTCT services for pregnant women.

> "These women get pregnant and come back, get pregnant and come back. We realized that in this moment of pregnancy women are seen as people who deserve care. That pregnancy turns out to be a special moment in their lives. A moment they don't want to give up. The care gets better inside the health service. She doesn't stand on a crowded bus, because of the big belly people will offer the seat to her. She'll be better treated by other people. So it seems that pregnancy puts her in a better and more interesting level in life. ………………… And unconsciously, that may stimulate women to get pregnant even being HIV+. It might sound crazy but we hear accounts like that. Because there's a big number of women who find out they are HIV+ in the Pre-natal and they come back later to the service pregnant again. Also, in Brazil, there's a total lack of family planning policy for HIV-positive women and, after these women have the baby they will be left behind.” Policy influential Rio de Janeiro [P18: bra.pol.idi.RdJ.tape21.txt]

> “[A provider should] monitor her and make her feel more valuable as a woman - cause in our culture, being a woman is not valuable, being a mother is; but not being a woman. They should show her that it's important to be a mother, but that the woman who doesn't have any children is equally important.” --Policy influential Recife [P25: bra.pol.idi.recife.tape28.txt]

While almost all respondents recognized that abstinence alone was not a viable long-term counselling approach for women, providers and women commonly spoke about how women initially felt that an HIV diagnosis meant the end of their sexual lives only to rediscover those needs with time and support. Nonetheless, many women and providers reported that in general, service delivery providers were somewhat uncomfortable and ill prepared to deal with issues of sexuality in the context of SRH counselling.

> “Professionals need to be better equipped; not only professionals who work directly on HIV/AIDS, but mainly those who don't……The medical professional, for example, which is rather technical about some questions, or even unprepared for the question of HIV/AIDS. To live without sexuality is not to live.” – Provider [P 3: bra.pro.idi.tape4.txt]

Equally difficult for many women, adolescent girls and male partners of HIV-positive women were discussions of issues of sexuality and HIV with sexual partners and family. Most women and adolescent girls in relationships had disclosed their serostatus to their partner. Nonetheless, women and young girls often spoke about the dilemma and fears they experience in initially having to disclose their status to partners and about the challenges of suggesting condom use with most partners. Some, particularly those with HIV-negative partners often chose not to disclose their status to friends or family out of fear and guilt and being blamed for wanting to infect a negative partner. Women with sero-discordant partners reported that men perceived they could not become infected from women and their refusal to seek services, including voluntary counselling and testing further complicated discussions of sexuality, leaving women to carry the burden of prevention for both.

> “I think it's complicated when the couple is sero-discordant because it seems there's nobody prepared to care for that situation. Even talking to the husband to use condoms, in such cases, he many times thinks the woman is daydreaming and he's not going to get infected. Every time it's she who has to talk about the risks” HIV-positive women, 44 yrs old, primary education, 1 child [R#2 (44 P 1) P 6: bra.com.fgd.women22-44.tape8+9.txt - 6:38]

> “I fight until today with my husband because he won’t accept using condoms. I've found out I'm HIV+ and he doesn't even accept to have the exam. I tell him that if I am positive, I got it from him, still he doesn't want to use prevention. I've already insisted so much but he doesn't use it. If I talk about this he gets mad and we start a war at home. I'm his wife so end up accepting that he doesn't use it despite knowing that it's harmful for me” HIV-positive woman, 28 years old, Recife, mother of 8) [R#7 (28 N 8) - P31: bra.com.fgd.women22-44.recife.tape34+35.txt - 31:14]

Quality of Existing SRH Services:

Reports of women’s access to and perceptions of quality of SRH services for HIV-positive women varied in the four study regions. Women often reported that they relied on and preferred specialized HIV centres, which were reported to offer quality preventive and treatment services specifically for HIV-positive women, including family planning, gynaecological services, and PMTCT. Referral mechanisms were also reported to be well organized for these services, however gaps were noted in the capacity of these HIV centres to offer comprehensive SRH care, particularly when involving voluntary interruption of pregnancy, treatment of unsafe and incomplete abortion, cervical cancer screening, screening for STIs in asymptomatic women, postnatal care, and breast cancer screening. As such, women often had to be referred to an RH centre.

Many complained about the discrimination and stigma they faced as HIV-positive individuals in these general RH centres. Long wait times, geographic distance to facilities offering care, and provider attitudes and discrimination were among the major complaints cited by women. Some women reported that while they knew that they had the right to be served first at these sites if they identified themselves as HIV-positive, they often hesitated to do so out of concerns about treatment received and lack of confidentiality. Adolescent girls also spoke about their concerns about confidentiality and feeling a lack of control over decisions involving their care since providers often prioritized their parent’s desires for them over their own.

While many commented on how much services had improved over time, some women reported that the progress was not adequate and expressed feelings of frustration over the lack of integration and coordination of services, particularly the limitations of certain providers to address their holistic health needs and consideration of women’s psychosocial needs.

> “The social assistant, for example, doesn't know how to answer a simple question about HIV. She ends up sending you to another professional.” HIV-positive women, 29 years old, IP, 3 children)[P 6: bra.com.fgd.women22-44.tape8+9.txt - 6:28] [R#1 (29 years old, IP, 3 children)]

> “I think the services should be more humane. They should see women as complete people and not only as reproducers or HIV+. Women are still devalued here in Northeast and have many situations of violence at home.”--Provider Recife [P32: bra.pro.idi.recife.tape36.txt]

Many women stated that as a priority they were more concerned with survival and supporting their families, which often left them with little time to seek the necessary care, particularly given the direct and indirect costs of accessing care. Most women and male partners reported that men rarely access SRH services due to similar issues, but compounded by their concerns about being labelled ‘homosexual’ for seeking HIV services.

Some providers and policy influentials concurred that while the efforts to improve PMTCT services have paid off, attention needed to be more broadly focused on offering a range of integrated quality SRH services for HIV-positive women and adolescents. Lack of integration of services was one of the biggest service delivery challenges reported by women who often did know where to go for specific services. While women liked the idea of being able to go to one HIV specialty centre for all their reproductive health needs, most providers and policymakers did not support the idea of vertical SRH services for HIV-positive women. Provider and policy-influential generally favoured a broader model of service integration, but suggested need for greater resources and training to achieve sustainable programmes.

> “I am not sure if we should offer a special SRH service for women and adolescent girls. I would say that a good, adequate sexual and reproductive health service has to include HIV+ women needs, lesbians’ needs, women who want to have a hundred children needs, a quality service has to meet women's different needs. I think this would be more adequate than offering a specific service for HIV+ women.”—Policy influential Sao Paulo [P 9: bra.pol.idi.sp.tape12.txt]

One policy influential spoke about issues of integration of SRH commodities and resources as one key step towards integration, particularly for making family planning methods more accessible to women within HIV testing centres and HIV/AIDS units.

> “The AIDS Programme gets to buy a certain amount of condom and gives part of it to women's programmes, but the contrary doesn't happen - women's programmes don't [do the same]. The opposite movement, i.e. AIDS units [don’t get} a big [shipments of] IUDs, cause the most recent studies state that IUD doesn't cause any problems [for HIV-positive women]. [This] doesn't happen in HIV Testing Centres, so it ends up that only the condom is available””-- policy influential, Sao Paulo [P 9: bra.pol.idi.sp.tape12.txt]

Family Planning, including Dual Protection:

Knowledge of family planning methods among women, adolescent girls and male partners was usually limited to condoms and sometimes pills and injectables. Almost all respondent groups, including providers and HIV-positive individuals had many misconceptions about the appropriateness of these and other family planning methods.

All respondents reported that condoms were the most appropriate method for all HIV-positive individuals, regardless of reproductive health intentions. Some providers simply stated that they were unclear what methods other than condoms could be offered to women.

Several providers also said they discouraged oral contraceptive use and/or all progesterone only hormonal methods because of perceived contraindications for HIV-positive women taking antiretroviral therapy (ART). Some providers were unsure of the nature of the contra-indication; some related it to potentially lower efficacy of the ARTs. Only one provider said that ART use was not a contraindication for FP method use and that women should have the choice of all methods.

> “Perhaps I wouldn't be able to tell you scientifically, but when one takes the antiretroviral, there is very little interference with contraceptive methods. Almost all of them are indicated to women. Perhaps one or two are more or less risky, but almost all contraceptive methods are indicated.” – Provider São Paulo [P28: bra.pro.idi.SP.tape31.txt]

Emergency contraception pills were mentioned by a few of the HIV-positive respondents by name, but none had actually used the method. All providers said that they never offered IUDs to HIV-positive women due to concerns about infection and bleeding.

> “I fear the infection [IUDs] can cause. Books say that the IUD must be avoided for its risks of infection, that it's too risky. The IUD causes too much bleeding and … can't be loosing too much blood every month. That's why I think that, again, the advantage of contraceptive with progesterone is that she won't menstruate. This means an even higher protection. You're avoiding that she become anaemic, for example.”—provider Brasilia [bra.pro.idi.brasilia.tape14.txt]

Sterilization, while initially the most common method recommended to HIV-positive women for birth limiting, was reported to be less stressed for women since the introduction of effective PMTCT programmes. A few of the women reported that they had been pressured into choosing sterilization despite having future hopes of bearing children. One woman who had been sterilized, reported post sterilization regret given the advances in PMTCT programmes.

> “In the beginning I really did a lot of sterilizations of many patients, though it actually happened from external pressure. We are actually pressured quit a bit. Then, as time went by, I became aware of its reality. I started working and saw that the patients were very well and that their children didn't carry the HIV.” Provider Brasilia [P11: bra.pro.idi.brasilia.tape14.txt]

The dual protection advantage of condoms was recognized by almost all respondents. Providers noted that they always insisted on condoms as the preferred method for HIV-positive individuals and often saw little reason to discuss other contraceptive methods. Women’s reports also suggested that providers rarely mentioned methods other than condoms. When asked about other methods, some provided tried to dissuade women from using methods, particularly pills and IUDs for pregnancy prevention. Several providers were also concerned that offering women a choice of contraceptive methods may encourage condom migration or cause women to stop using condoms altogether. Some providers and policy influentials stated that they recognized the difficulty of condom use for women; others failed to recognize the limitations of condoms alone or suggested that meeting individuals' reproductive intents were secondary to broader issues of HIV prevention on a population level.

> "I don't know whether we have a sort of - how could I say it to you? - a rather specific role, and perhaps we may even scare patients a little, but since we work on prevention, our greatest apprehension is that they may infect someone else, other people, for many of the women we see have promiscuous behaviours. We have patients here who are prostitutes and aren't concerned with their partners. We try to get it thru to them that they have to prevent the epidemic, the contamination. Rather we work on the preventive medicine part, on prevention of infection and gynaecological cancer. Family planning is not our priority." –provider Sao Paulo [P30: bra.pro.idi.SP.tape33.txt]

HIV-positive women and adolescent girls commonly noted the personal challenges with using condoms. Women reported particular difficulty in negotiating condom use with regular sexual partners and were generally more concerned with the risk of infection to partners rather than their own risk of re-infection. Male partners were clear about the risk of infection or re-infection but reiterated their strong dislike of condoms; only a few said that they used them consistently or when their partners insisted on use.

Reasons for non-use of male condoms were attributed to the difficulty in negotiating use of a method that depended on men's willingness and participation, dislike (or partner's dislike) of the method due to hindrance of sexual pleasure, and male partner refusal to use the method. A few women also said that they had similar problems with using female condoms; a few also reported difficulty obtaining the method regularly at an affordable cost. There were also fears associated with the potential consequences of suggesting condom use, including partner suspicion about fidelity, violence, and abandonment by partners.

> "Most HIV+ women don't use [condoms] because they are afraid of losing the partner. They do what the male partners want and that's it. Moreover, many trust the male partners have sex only with them. That's why I said we can't trust anymore. If HIV+ women don't use, it's not because they don't know they can get re-infected, but because they are afraid of losing the partner. Fear of being alone."—29 year old HIV-positive woman, Recife, IP, 2 children) [P31: bra.com.fgd.women22-44.recife.tape34+35.txt R#2 (29 IP 2)]

Women and adolescent girls suggested that much of the difficulty in negotiating condom use had to do with issues of gender inequalities in relationships, taboos around discussing sex and sexuality, and stigmatization of condoms as the method used by those who are promiscuous or are infected. Several women said that condom use was still equated to lack of trust or reason for distrust.

> “They do not have negotiation power. They depend on their husbands, they live for their kids, they are spanked by their husbands. They are already infected, why use a condom? So, it's all about negotiating.”—34 year old HIV-positive woman, primary education, 4 children) R#3 (43 P 4)

> “When we ask them to use condoms, we have to explain why we want them to use and that's very constraining. Boys today charge women with responsibility for everything. I've got some friends who even choose to have relationships only with HIV+ guys so as to be able to have a more open relation, to be able to talk more about the problem.” HIV-positive 19 year old, Rio de Janeiro, IP, 2 children [P34: bra.com.fgd.women15-19.RdJ.tape38+39.txt - 34:8]

> “I think that it's quite complex for women. Women are still submitted to men, and a woman is driven by emotion and men, by reason. So, if she loves him and he approaches her smoothly, trying to convince her not to use a condom, he manages to convince her not to do so, even if she knows she's supposed to use it. She gives in for love.” HIV-positive woman 39 years old, secondary education, 1 child [R 2 bra.com.fgd.women22-44.tape10+11.txt)

Some providers and policy influentials recognized the complexities of partner relations and the added dual burden placed on women as the ones who more commonly interface with health care services. One policy influential suggested that there was a need for more method options for women for HIV prevention; another saw it as a matter of better meeting the needs of individuals with the existing range and combination of methods.

> “It's not as if their needs to be a new method available, their needs to be a new way for them to be available. Their need is a matter of saying: Listen to these HIV+ women and figure out what is the best way to approach them.” Policy influential Rio de Janeiro [P17: ra.pol.idi.RdJ.tape20.txt]

Sexually Transmitted Infections (STIs):

Other than counselling about the importance of condom use for STI prevention, few mentioned offering routine asymptomatic screening of HIV-positive individuals for STIs. Pregnant women were reported to be routinely screened for syphilis as part of antenatal care; otherwise, the syndromic approach to STI diagnosis and treatment was most commonly discussed by providers. Women and men generally associated STIs with symptoms, including discharge, pain, or bleeding. None recognized that STIs could be asymptomatic or the importance of screening HIV-positive individuals. A few women said that they were routinely tested as part of their annual gynaecological visit, but the mechanism for such screening was not clear. Comprehensive testing and treatment was reported to be available at STI centres by referral for HIV-positive women.

Prevention and Treatment of Breast and Cervical Cancer:
Providers commonly spoke about responding to women's cancer needs by referral upon the appearance of symptoms, but few providers interviewed recognized the importance of prevention (asymptotic screening for cervical dysplasia and breast examinations for breast cancer) for women and adolescents who were HIV positive.

Some women said that they received routine breast examinations during annual gynaecological exams but few reported knowledge of need for it or how to perform self breast examinations. Some of the women with a history of breast nodules or breast cancer spoke about the difficulty in getting timely referrals to specialty centres for mammography, biopsies and cancer treatment.

> "Prevention works, but for the ones who already have a nodule in the breast, it's more complex. It's another challenge from that moment on. We don't know where to go." –39 year old HIV-positive woman, secondary education, 1 child) [R#6 (39 S 1) – P 8: bra.com.fgd.women22-44.tape10+11.txt]

Women and male partners commonly equated cancer prevention with early diagnosis of cancer. Few women knew of either the importance of asymptomatic screening for preventing cervical cancer or the increased risk of the disease among HIV-positive women. Some women spoke about their fears of vaginal examinations as reasons why they did not present for gynaecological visits; many did not equate vaginal examinations with cervical cancer prevention.

Only women who had been diagnosed with cervical dysplasia knew that screening for cervical cancer could be performed during annual gynaecological visits. Otherwise, all woman and male partners equated cervical cancer prevention as early treatment of cancer, precipitated by the appearance of symptoms such as bleeding, abdominal pain or discharge. Some of the women and adolescent girls who had been diagnosed with cervical dysplasia spoke about their difficulty in getting appointments for cervical biopsies and treatment.

Unintended Pregnancies:
When asked about safe abortion services, almost all providers spoke about the illegality of abortion services under most circumstances in Brazil, referring more to postabortion care services by referral. Many also cited personal and

religious objections to elective abortion. Some said that it is only provided in the case of rape and to save a woman's life, but how women would access abortion even in these cases did not seem clear. Policy influentials and providers recognized that women, particularly poor women, often had to resort to unsafe and clandestine abortions given the lack of access to safe termination of pregnancy services in the public sector.

Several women had experienced postabortion care services and some reported negative provider attitudes towards women presenting for postabortion care. A few women and one male partner spoke about the risks created by women's lack of access to safe abortion services.

> "I had an abortion [by] woman who lives on the other side of town. It hurt so much and I thought I'd die" (HIV-positive woman, Recife, IP 4 children) (tape 34+35)

Some women commented on the challenge and hypocrisy of the abortion situation; feeling they had even fewer reproductive health options as HIV-positive women who are discouraged from becoming pregnant but also not allowed to safely terminate an unwanted pregnancy, particularly for those lacking the financial means to access services in the private sector.

> "This abortion stuff is a great hypocrisy. It's considered a crime but who doesn't know about someone who has already done an abortion or where you can do it? If you have money, there are some doctors who do that safely. If you don't, you go to a [unofficial provider] and can die or have other problems."—-35 year old HIV-positive woman, Recife, IP, 2 children) [P31: bra.com.fgd.women22-44.recife.tape34+35.txt R#12 (35 IP 2)]

Maternity Care, including PMTCT Services:
The changes and improvements in pre-natal and PMTCT services were praised by many of the women who delivered in specialized PMTCT centres and recognized as a major accomplishment by policymakers and providers. Despite this, many felt that further improvements were still needed.

Almost all women who accessed PMTCT services were identified through antenatal voluntary HIV testing and counselling. A few women were tested using rapid tests at the time of delivery as noted by women and providers. Overall, women and adolescents were informed about the various components and advantages of prevention of vertical transmission. For many, advances in PMTCT not only offered the opportunity to deliver a potential healthy child but allowed women to access services that were better than other services they had previously received as HIV-positive women. Some women and providers still felt that while access to services had improved, the focal point of PMTCT programmes was still the child rather than the mother and child

> “I think that their rights are still not respected, and that there aren't many people concerned with sexual and reproductive health of HIV+ women. They are most concerned with transmission from mother to child.” Provider Recife [bra.pro.idi.brasilia.tape15.txt]

One issue noted as challenging by several women and adolescents was the lack of ability to breastfeed per national PMTCT norms. Despite being provided with 6 months infant feeding formula at no charge, women said they struggled with the social stigma and discrimination against women who did not breast feed their children. A few providers recognized this challenge.

> “It's hard for us. We have to take medicine, to use prophylactics, whether or not we want to, so as to reduce the risk of contaminating the baby, to have an injection at the time of delivery. It's hard for us to have a pregnancy in such a situation... In my case, harder than that, harder than the Caesarean, was not to be able to breast-feed. That was too hard. That was the worst thing to me, not to able to breast-feed, to have to bandage my breasts. It was as if I weren't a real mother, you see?—19 year old woman, IP, 2 children) R. #8 (19 IP 2) P34: bra.com.fgd.women15-19.RdJ.tape38+39.txt

> “We approach the [issue of breastfeeding], for that deeply touches them, since the fact of not breast-feeding is associated, by many of them, to the very process of not being a hundred-percent mother”--provider 3: bra.pro.idi.tape4.txt

Women commonly spoke about the need to make information about PMTCT services available to all women, not only those considering pregnancy or who are pregnant. Many felt that this information would not only help communities understand that HIV-positive women could have healthy babies, but also may encourage more women to seek pre-natal care.

Information, Education and Communication (IEC) and Counselling and Psychosocial Support:

Respondents cited several sources of information on HIV prevention, including print media (pamphlets, newspapers, magazines, and posters), visual mass media (soap operas, television, radio, theatre groups) and word of mouth from NGO staff and providers. Respondents across groups noted that IEC campaigns tended to become available around specific events such as World AIDS day or Carnival, which was perceived as too inconsistent and infrequent by most respondent groups. Many also felt that IEC messages were often too vague in their general prevention messaging, depended on fear-based prevention techniques, and rarely addressed the needs of those who were already HIV positive. Few print or visual media sources specifically addressing SRH of HIV-positive women and adolescents were cited. A magazine *Saber Viver* was commonly cited as one IEC resource for HIV-positive individuals, but this resource was no longer being printed by the NGO that produced it due to limited funding. Nonetheless, numerous respondents recognized the importance of public education campaigns in spreading accurate information and normalizing access to services. Some felt that in the absence of clear objectives and quality services to support behavioural change messages, IEC campaigns would have limited impact.

> “I think [media campaigns} are rather restricted, because the public they reach are sometimes very restricted, because they don't have a continuity. I think that the great problem of campaigns is this: besides not having continuity, they don't offer alternatives. For example, there are many campaigns aimed at women for prevention of vertical transmission, but there few services which satisfactorily offer services to women.” Provider Sao Paulo [P28: bra.pro.idi.SP.tape31.txt]

Numerous women, adolescent girls and male partners said they would prefer to receive more information via word of mouth and counselling, particularly from providers rather than from broad media campaigns. Many reported that quality counselling, including information and psychosocial support was rarely offered as part of services. Some said that they turned to PLWH networks and support groups to help them cope with the everyday struggles of discrimination and unmet needs. Some relied on their family, community, and faith based organizations for psychosocial support. Many, particularly those who did not disclose their status to their family, reported feeling abandoned by those who were supposed to be their primary sources of support. Some reported that while they were deeply faithful, they did not agree with the way faith-based organizations approached the issue of HIV/AIDS prevention, including the views of some on family planning and condom use.

> “So religion, on the one hand, is a positive element which gives sense to the lives of those women. For they are in a situation of sufferance and their religion strengthens, comforts, even offers them some opportunities of feeling rather fulfilled. But, on the other hand, it is where judgments come from. And several times, after that experience with religion, they end up thinking that AIDS is a punishment for something wrong they have done in their lives.” Policy influential Sao Paulo [P10: bra.pol.idi.sp.tape13.txt]

Provider and policy influentials also recognized the importance of this lacking element of counselling and psychosocial support in healthcare to help women cope with the daily challenge of discrimination that hinders their ability to exercise their human and reproductive health rights.

> “One of the first things women need, even the youngest ones, is a sense of empowerment she needs to feel that she exists in the world, that she's able to manage some defence instruments and some

> survival instruments in this world that discriminates so much.” Policy influential, Sao Paulo (P23: bra.pol.idi.SP.tape26.txt - 23:12)

The need for more peer-based counselling and outreach and for better sexuality education in schools was also mentioned by several women and adolescent girls, as well as by some providers and policyinfluential as a way to begin to address the root causes of women’s vulnerability to HIV infection.

Policy Priorities and Programmatic Needs:
Providers and policy influentials affirmed women’s concern that while a great deal of effort had gone towards issues of HIV prevention, attention to the needs of those living with the virus, particularly women, was still lacking. Most believed that the gap between what is recognized as women’s rights and what actually exists in terms of services had more to do with the lack of available resources, political will and sufficient advocacy by organizations working on women’s and health issues, rather than controversy.

> “I don't think there's an active opposition to talking about the issues. I think what it is, is more with so many other groups dealing with their own concerns. I think it's a group that's falling through the cracks, so to speak.” Policy influential Rio de Janeiro (P17: bra.pol.idi.RdJ.tape20.txt)

> “I would say that in terms of rights, people generally agree with that. I would say that if they sat and think about it, or if they try to implement it at the level of health services, there's still a big vacuum between echoing the rights and saying "Yes, I agree", and actually making some changes at the level of services. Particularly public health services and then make them happen. I'd say there's a huge gap between the two.” Policy influential Rio De Janeiro(P17: bra.pol.idi.RdJ.tape20.txt

As such, policy influentials and some providers felt that the voice of HIV-positive women and adolescent girls and those of their advocates, including health providers, feminists, PLWH groups, needed to be raised on these issues, which suggest a need to re-examine existing and future programmatic and policy strategies related to both HIV prevention and women’s and girls’ rights.

> “It's not just a matter of public health. But I think that women need to organize themselves a little more. The struggle against men, health professionals, is still a very great one.” Provider Sao Paulo (P27: bra.pro.idi.SP.tape30.txt)

> “The social movement is fundamental to monitor, to follow and be ahead of these fight processes for public policies for PLHA.” Policy influential Rio de Janeiro. P20: bra.pol.idi.RdJ.tape23.txt

While some respondents across all groups were disheartened at the slow pace of change in the fight against HIV/AIDS and discrimination, many seemed encouraged by the progress made to date by health services and society on the complex issues of HIV prevention and reproductive rights.

> “We have two big fights: beat the virus and fight against prejudice. But beating prejudice is too slow.” –48 year old HIV-positive male partner of HIV-positive women, primary education, no children. P 5: bra.com.fgd.seroconmales.tape6+7.txt

> “For health is not only a biological matter, it has a social determination which passes through all economic and educational matter. It is not only biological, as we, physicians, are taught so. I think that for the time being we have to fight, and that we mustn't give up, for I think that we have advanced up to now, but have done it so at a extremely slow pace.”—provider Sao Paulo P27: bra.pro.idi.SP.tape30.txt

Many respondents reiterated the importance of multi-sectoral collaboration and strong political will to meet the holistic rights and SRH needs of women and adolescent girls by integrating services in strategic planning and programme development and collaboratively working to eliminating the existing barriers to care.

C. KEY FINDINGS: ETHIOPIA

Sexual and Reproductive Health Intentions and Reproductive Rights: Most respondents in Ethiopia reported that choices about fertility and family size were mostly the responsibility of the man in the couple. Only a few believed that the choice and options of childbearing lay primarily with women and many women reported a great deal of family involvement and sometimes pressure, particularly from in-laws in favour of childbearing. HIV-positive women and male partners of HIV-positive women had varying views about the ideal family size, ranging from 2-12 children; most common was the belief that couples should have as many children as they could financially manage and depending on the ‘will of God’. There was very strong preference for male children over female children. As fertility and reproduction are highly valued, the inability of a woman to have children or have male children was generally seen as justification for abandonment or divorce by some.

> “If a mother gave birth to a male child every one says congratulations but if it is female child it is said "Tihun Beka" (that's ok) --Woman, 29 yrs old single woman with no children, Secondary education G7: (29, S, Unk, 16th, 0)P26: eth.com.fgd1.women25-55.txt - 26:21

Despite the importance of fertility and reproduction and personal desire to have more children, most women and male partners of HIV-positive women said that were willing to settle for not having any children due to their infection or being contented with the existing number of children or the last pregnancy (for those screened through antenatal care). Reasons for limiting births included fear of community judgment and discrimination, fear of vertical transmission to children and concern about their physical and economic capacity to raise children given the uncertain nature of disease manifestation. Some considered further childbearing acceptable in situations where one partner was sero-discordant and therefore available to raise the child.

> "First of all person living with the virus according to counselling given, they should not totally give birth. It is quite advantageous not to give birth throughout their life with respect to the care and support they given to their family because if they give birth it will disturb his mind and his family's." –Male partner, 34 yrs old [G.3. (34, SC, S, 2). P23: eth.com.fgd.males1.txt - 23:13]
>
> "Maybe things are changing now but no one encourages or at least supports a person living with the virus giving birth. Even health professionals advise you to stop childbirth if they know that you are HIV-positive so I think it will be difficult for a woman living with the virus to access the service. It would be easier for HIV-positive women if others could understand their needs and leave the decision to them."—Woman 35 yrs old, sero-concordant partner, 3 children [R2: (35, W, SC, 12TH, 3) P27: eth.com.fgd2.women24-44.txt]

All women and male partners stated that they had been clearly counselled by providers to avoid pregnancy and for that matter sexual intercourse. Unmarried women reported that they were generally not allowed or expected to marry or have sexual contact. Several married women reported abandonment by husbands and family upon testing HIV positive.

> "I got married after learning that I am HIV positive. Everybody was opposed to my marriage. People were asking me why I needed to get married. Saying you are going to have an HIV-positive child. Why not take care of yourself? They don't encourage us to live positively. ……I know you get respect if you are married but I was blamed & opposed because I am HIV positive." – Woman 21 years old, no children, sero-concordant partner [G.4. (21, M, SC, 6th, 0) P25: eth.com.fgd1.women18-25.txt]
>
> "As to me the best way to prevent HIV & sexually transmitted disease is to abstain from sex. If this is impossible the person has to use condom with each sexual intercourse."—Woman (Resp 6) P25: eth.com.fgd1.women18-25.txt - 25:5

Misinformation about sexuality and reproduction were commonly reported by respondents, many of whom had been counselled to practice abstinence, severely limit the duration and frequency of any sexual contact for medical reasons, or reduce having a satisfying sex life. As such, women and male partners of HIV-positive women spoke about how they struggled with issues of sexuality and sexual relationships. Many had feelings of guilt over having sexual desire, spoke about the difficulty they had in abstaining or limiting forms of sexual interactions as they were counselled to do. Many reported that they were counselled about how sexual desires and sexual rapport weakens the immune system and makes them more vulnerable.

> "Safer sex means having sexual intercourse with limited frequency not more than once in a week & using condom this is to satisfy their sexual desire with out having a child." -- HIV-positive women 24 yrs old, 1 child, sero-discordant partner {G.2. (24, M, SD, 7th, 1)"— P25: eth.com.fgd1.women18-25.txt}

> "I have been counselled that the main cause that is shortening life of the married couple is sex and I was advised to stop sexual relationship. So I have made the decision after receiving the advice. I am glad that I did because it helped me to stay healthy." Woman, 32 yrs old, 1 child [P27: eth.com.fgd2.women24-44.txt R6: (32, D, SC, 8TH, 1)]

> "From the discussion with my friends and my counsellor I understood that sex is dangerous for HIV-positive women in different aspects, my counsellor told me that having one act of sexual intercourse will need the same amount of energy to that you need to run one full round foot ball playing ground. Then as I have started to live I am thinking of marrying an HIV-positive person and to have one child, but I know we have to have sexual acts within limits and to use condom except for some time till I become pregnant so that both of us won't face a problem." --Woman 30 years old, no children (G.6. (30, U, SC, 12th, O): P26: eth.com.fgd1.women25-55.txt

Interviews with providers and policy influentials suggested varying views about HIV-positive women and couples making reproductive choices, including the right to childbearing. Most providers and policy influentials said that HIV-positive women and couples are discouraged from getting pregnant or having children because of the risk of infection to the child. Some disagreed in principle with women's right to fertility, but said they would still provide care, including PMTCT services to HIV-positive pregnant women in order to protect the child. Only a few policy influentials and providers believed that with advances in PMTCT HIV persons should have the right to have children if they desired them, particularly for women who had no children. However, providers generally felt that they would only support a woman's choice to become pregnant upon complete clinical examination, which they said rarely happens, since more commonly, women just "turn up" already pregnant despite counselling.

> "We give them advice on ways to live peacefully with the virus. First we don't encourage them to give birth. This is because she could transmit the virus to the child. Now there is PMTCT service and this might avoid the fear of infecting the baby, however pregnancy by itself may not always have a peaceful outcome so it could be dangerous to her health. It will make her weak immunity much weaker so we don't encourage women living with the virus to give birth."-Provider [P 4: eth.pro4.idi]

> "From the point of view of reproductive health rights, how many children to have, from whom to have, when to have them, they should be decided by the mother herself. She can not be devoid of this right because of the fact that she is positive."—Provider {P11: eth.pro10idi }

Most women who participated in the research had disclosed their status to their male partners, some after some delay; many women were widowed or divorced due to HIV infection. Women with sero-discordant partners often did not disclose their status out of fear of discrimination and abandonment. Very few had disclosed it to their community or outside the immediate family unit out of fear of rejection and discrimination as evidenced by the experience of several women. Women spoke about the difficulty in communicating about issues of sexuality with partners and feeling pressure to accept whatever situation they were given as an alternative to complete abandonment due to community pressure.

> "When I told HIV test results to my best friend at first she immediately said to me you have to separate from your husband 'why do you need to live with together if you are no longer be sexual partners'. My parents & relatives also influenced me to leave my home and to live with my parents. This shows that no one understood that people living with HIV has sexual desire." –-Woman, sero-discordant partner, 2 children) G.7. (24, S, SD, 12th, 2kids w 1 SC) P25: eth.com.fgd1.women18-25.txt

> "When they see women living with a virus with a man even without knowing the kind of relationship they have they started gossiping. They say she is going to pollute him so they are not supportive." –Woman, 30 years, married, 2 children (30, M, SC, 11TH, 2) P27: eth.com.fgd2.women24-44.txt

> "No one supports us and they don't leave us alone. On sexual issues people do not look at us as human beings." --Woman 23 yrs old, 3 kids) -- G.5. (23, M, SC, 7th, 3kids, 2SC) P25: eth.com.fgd1.women18-25.txt

Quality of Existing SRH services:

SRH services for HIV-positive women were reported to be available by providers and policy influentials in both the public and NGO sector. In the public sector, SRH services including VCT, antenatal care, PMTCT, post-partum care, and family planning, were available. STI diagnosis through syndromic management was also available as was treatment of miscarriage. A couple of NGOs were reported to also provide a range of SRH services for women, (FP, STI treatment, etc.) including HIV-positive women. However, most women and male partners did not know where services were offered or preferred to not access care due to negative experiences with previously received care. Most spoke about how they avoided accessing health services except for emergencies or serious medical problems and relied heavily on PLWH NGOs and networks to get their information that they reported was inaccessible in the public sector.

> “What makes their condition more complicated is the way in which reproductive health services are given, where they are given, the institutions providing these services are not publicizing their services adequately. Because of these people they just assume beneficiaries are coming to them. Both women and adolescent girls, elder women living with the virus and those not living with virus, which facility, place, what kind of services, why, at what level. Their knowledge is very limited.” Policy Influential [P18: eth.pol5]

The most commonly cited reasons by HIV-positive women and their male partners for not accessing healthcare were concerns about lack of confidentiality, the negative attitudes of providers, and the stigma and discrimination associated with seeking care. Other barriers included the financial, both direct and indirect cost of seeking care, long waiting times and lines, the distance of centralized mostly urban services, and socio-cultural and gender norms limiting women’s access to services without the permission of or presence of a male relative.

> “When my wife told me what happened I was about to beat that doctor, he is a specialist and big person. He told to my wife in public, "you have to take your child home as he is HIV positive."—Male partner (sero-concordant, 3 children, P24: eth.com.fgd.males2.txt - 24:38 G.4. (35, SC, 12TH, 3).

> “We have problem getting care if the health worker know the HIV status of the patient, especially if an HIV-positive person went to the clinic for sexually transmitted disease they mistreat the person. Some health institutions also label the room as treatment room for HIV - positive people. In my opinion, no HIV-positive person will go there because the stigma is so intensive. Training has to be give for health workers.” –Woman 25 years old, no children) G.1. (25, M, Unk 13, 0) P25: eth.com.fgd1.women18-25.txt

> “There are so many factors that prevent service utilization one is the geographical accessibility of the health institution, the economic accessibility including transportation fee, the work load of the mothers at household level, the awareness of the young girls and mother's about the benefits that they get from the services. The other issue is stigma and discrimination.” Policy influential P22: eth.pol.idi

Many said that as much as possible they tried to not disclose their HIV status to providers to avoid negative care. For similar reasons, several indicated that they generally preferred to first seek care from a traditional healer for certain issues such as infections and unintended pregnancy, before seeking medical care. Women also spoke about not getting complete information or quality care from health providers, some of whom were perceived to reluctantly offer care and examination to avoid contact with HIV-positive patients. Women also reported receiving little empathy and support for their ailments and needs, which were commonly attributed to their HIV infection.

> “[There should be] training for health workers because health workers do not give us appropriate care if they know that the person is HIV positive, some health workers also say for every illness this is the nature of the HIV infection. Because of this we are not telling our HIV status to health worker who are treating us. –Woman, 24 yrs old, 2 children [G.7. (24, S, SD, 12th, 2kids w 1 SC)]

Policy influentials and providers commonly recognized the limitations of existing services, which was generally attributed to the overburdened and resource poor nature of the health system. Many recognized stigma and discrimination by providers as an obstacle to care alluding to recent interventions and training of providers to address these issues.

> “If we look in to the situation in general in the country we can't say the existing services address their needs. There is shortage of trained human resource most people working in family planning clinics especially those who are working in rural areas haven't received any training after they graduated. There is shortage of equipments and materials as well so it is really difficult to say the existing services address their needs. Regarding the services that we provide we are working by integrating preventive activities with care and support activities.” - Policy influential P22: eth.pol.idi

> “There was extreme fear and health workers used double gloves and had expressions to the extent that patients were feeling ashamed. Well, it is good to protect oneself but should not as such be exaggerated. But these events are nowadays somehow of these issues have been solved by raising this issue and conducting thorough discussions about it.”—Policy influential [P19: eth.pol6.idi]

While some women and men reported a desire to be able to access existing services without discrimination, several women and men expressed preference for separate specialized care for HIV-positive individuals where they could access all their reproductive health care and avoid contact with a range of providers for the SRH needs. Some also suggested the need for similar specialized services for young women, including adolescents. Equally important, many women and male partners reported the need for decentralization of many SRH services to the secondary and primary care levels.

> “There has to be way for HIV-positive woman to use the existing service equally with HIV-negative woman.” Woman, 24 yrs old, 2 children [G.7. (24, S, SD, 12th, 2kids w 1 SC) P25: eth.com.fgd1.women18-25.txt - 25:31]

> “What should be improved is that, health posts, especially, those agencies doing this job should broaden the horizon of their services. They should get into the community and teach them about reproductive health so as to increase their awareness.” --Male partner, 29 yrs old, 0 children P23: eth.com.fgd.males1.txt G.5. (29, SC, S, 0).

Aside from efforts to integrate FP and STI prevention into antenatal care and PMTCT for HIV-positive women, most SRH services were not offered in an integrated manner and clients often noted the lack of communication and continuity of care. One NGO was reported to offer a range of SRH services, but without focus on care and issues for HIV-positive individuals, who were commonly referred to tertiary facilities for most clinical care and treatment services. Most policy influentials, providers and women did not see the reality in using existing limited resources to set up vertical SRH services for HIV-positive women, preferring integration of services with greater access for HIV-positive persons. Some also added that this approach was more appropriate given that most women did not really know their HIV status and that those who did may not be willing to use specialized HIV services. Equally if not more important in the minds of some respondents was the need for decentralization of services so that individuals did not have to come to tertiary facilities for care.

> “The sexual and reproductive health services given to HIV-positive women and adolescents should be offered in integrated manner and should be offered by professionals who have adequate information knowledge and skills to provide such services and the service should go closer to the community.” Policy influential [P22: eth.pol.idi]

> “HIV and reproductive health services can connect. But to me, rather than making the reproductive services specific to HIV, it is better to expand the services as much as possible. Most often majority of them do not know their status or do not want to expose themselves. They

> come here just like any other person and get the services. Therefore, we have to advocate means of prevention of sexually transmitted diseases
> as they are closely related to HIV. In fact this information should be given not only to those living with the virus but also to those without the disease."--Provider {P11: eth.pro10idi }

Family Planning, including Dual Protection:
HIV-positive women's and male partners' knowledge of family planning methods were mostly limited to condoms, in some cases, oral contraceptives and implants. Very few providers said they ever recommended a contraceptive method other than condoms or they recommended abstinence, mostly due to misconceptions about appropriateness of most contraceptives for women who were HIV-positive or on ARVs and also fear that that discussing other methods may dissuade clients from using condoms.

> "The information that you get from health professionals is not complete. They don't tell you about other methods they just tell you that you should use condom when they find out that you are HIV positive. It would be good if they tell you all the options you have and leave the decision to you."—Woman 25 yrs old, 1 child {R6: (25, U, UNK, 8TH, 1) P28: eth.com.fgd2.women18-24.txt}

> "There are different methods. Generally if a person become HIV-positive and developed AIDS there are two family planning methods that we advise. These are condom and as pills usually interact with ART drugs so we advise for others methods. In this we advise them to take condom with other methods, which is usually is dual method"--Provider [P 8: eth.pro8.idi]

> "The pills & injectables have a problem for HIV-positive woman especially if she is on anti HIV drugs it may have side effect & bring health problems so this brings not to have choice regarding family planning methods."—Woman (24 yrs old, no children) P25: eth.com.fgd1.women18-25.txt G.1. (25, M, Unk 13, 0)

Very few providers discussed other family planning methods as alternatives to women who could not use condoms or as a second method ('dual method' use for dual protection) to prevent unintended pregnancy. Some women spoke about their struggle to get information on other methods from providers.

Most providers interviewed were not sensitive to the challenge women faced in negotiating condom use and abstinence with male partners. Both these issues were commonly cited by both women and male partners. The advantages of dual methods and hence the practice of offering women two methods were rarely reported by providers.

> "Like most women in this community, condom is not their first choice. Either they want contraceptive injection or tablets. But after we explain the multiple advantages of using condom then they decide to use condom." –Provider { 5: eth.pro5}

> "What is the use [of using pills and condoms]? There is not help, pills will not help her because condom will prevent pregnancy as pills is take to prevent pregnancy but not for sexually transmitted diseases so there is not use the pill. If that is to prevent pregnancy if she uses condom there is no problem." – Provider [P 2: eth.pro2]

> "By chance, unprotected sex happens. When [only] using condoms, a woman will have a problem. So other contraceptive methods should be used as backup means. But this should be based on choices of clients. So relaying on condoms could put the life of your wife to get unplanned pregnancy if a condom breaks."—Male partner, 34 yrs old, 2 children P24: eth.com.fgd.males2.txt G.5. (34, SC, 11TH, 2).

Women often alluded to their strong desire to protect partners from infection or re-infection as their primary reason for using condoms. Still, their accounts suggest tremendous difficulty and challenge to negotiating condom use. Gender power dynamics and strong dependency on men as the head of household left many women fearing abandonment and/or violence as repercussions for suggesting or insisting on condom use. Very few male partners said that they used condoms consistently or at all, mostly due to their dislike for condoms or lack of perception of risk of infection.

> "I have decided to use condom but my husband is not willing to use it. We have a lot of condoms at home but we never use them. Now he is taking treatment for the HIV virus and I have tried to explain to him that the virus we have may be different and it might create more problem to us but he still refuses to do so. So although I want to practice safer sex using condom I couldn't. I am a housewife who doesn't have any source of income and I am totally dependent on him so I don't have a choice. However I am using contraceptive injection to prevent pregnancy." – Woman, 30 yrs old, 3 children) [P27: eth.com.fgd2.women24-44.txtR3: (30, M, SC, 11TH, 2)]

> "Even if she wants to use condom it becomes difficult because she has to give him reasons why they need to use condom. This is very difficult for most women. They are economically dependent on men and they don't know how their husbands would react when they hear they have HIV." –Woman, 40 yrs old, 3 children [P27: eth.com.fgd2.women24-44.txt R4: (40, M, SC, 0TH, 3)]

The female condom was mentioned by a few providers as one possible alternative that allows women more control. Few women had heard of this method and one reported that it was inaccessible due to cost and limited availability.

Sexually Transmitted Infections:

Aside from routine antenatal syphilis testing for women, no protocols were indicated by providers for routine screening of HIV-positive person for STIs in the absence of symptoms. The syndromic management approach was used to diagnose STI in sites. Women and male partners had little information about sexually transmitted infections and their relationship to HIV infection. Several admitted to self treatment for STIs after consultation with a pharmacist or traditional healer to avoid the embarrassment and hassle of seeking medical services.

> “Probably, the sexually transmitted disease will be evident after 15 days. There may be change around their sexual organs and at that time she might notice it. If she is not shy she can go and be treated. If not, she buys ampicillin from shops and takes it. This is how most women are affected. She will not go to the health centre telling them that she has the disease.” Male partner, 39 yrs old, 1 child) P23: eth.com.fgd.males1.txt G.4. (39, SC, S, 1).

Prevention and Treatment of Breast and cervical cancer:

Cytological or visual screening of asymptomatic women for cervical dysplasia was also not noted by any providers, who often linked cervical cancer screening with treatment or testing upon the presentation of symptoms. Most public facilities said that while the issues were important they did not usually include in their services and usually referred women to tertiary facilities if they had symptoms of cervical or breast cancer (i.e. when it is already a bit late). One NGO offered testing for those with symptoms but had no protocol for routine screening of women at risk in the absence of symptoms. Self-breast examinations were also taught by this NGO but not noted by public sector providers. With very little information available about the relationships between HIV infection and cervical dysplasia and breast cancer, few women and male partners knew that they should be screened, commonly referring to detection by early signs as prevention. Limited treatment services were reported to be available for cancer in tertiary facilities.

Unintended Pregnancies:

In Ethiopia legislation restricts termination of pregnancy to cases of rape and threat to the mother’s life. None of the providers interviewed said that they performed terminations of pregnancy but some reported offering or being trained to offer post abortion care. Women and men spoke about the toll of unsafe abortion on their lives and the lives of friends given the difficulty in accessing safe abortion services and the common reliance on traditional healers or community providers. Some women believed that having a safe abortion as an HIV-positive woman was even more complicated by the fact that some health workers did not want to provide them with clinical care in general for fear of infection, limiting, for example, use of services to address complications of unsafe abortion.

> “A friend of mine is HIV-positive and went to one of the hospitals to ask for abortion service and told the doctor that she is HIV-positive & the doctor refused to help her, she went to traditional healer & took some medication & died because of this. So this is a very problematic issue.” – HIV-positive woman, 21 years old, no children) P25: eth.com.fgd1.women18-25.txt G.4. (21, M, SC, 6th, 0)
>
> “Such a service (abortion) is offered in the hospitals for those who are raped and become pregnant. However, this traditional abortion service is causing deaths of many women. We losing many of our sisters because they go to the traditional healers since they do not want their parents know the pregnancy.” –Male partner, 34 years old, 2 children P23: eth.com.fgd.males1.txt G.3. (34, SC, S, 2)

Maternity Care, including PMTCT Services:
Providers and policy influentials noted the impact of introduction and expansion of PMTCT services on the lives of HIV-positive women. PMTCT services, mostly offered in select tertiary sites and in partnership with community organizations were praised for having given women greater reproductive choices and also promoted VCT services.

> “It was very difficult before, especially when a woman knew that she was HIV-positive after becoming pregnant. It was really difficult because there wasn't much you could do other than telling her that she could be lucky and that she could have a healthy baby. Now we have PMTCT so this makes the effort to reassure her easier.” -- Provider P 5: eth.pro5
>
> “People used to be very angry with her if they find out that a pregnant mother is HIV positive. This is because every one worries about the transmission of the virus to the child. They used to blame them for bringing one more child to suffering. But now with PMTCT, I think things are getting better.” – Provider [P13: eth.pro12.idi]

Only a few of the women who participated in this research had experience with PMTCT in recent years. Some, who had used services, spoke about appreciating the care, which was better than other services. While women reported that services were more available in recent years, they felt that they were too geographically centralized and not well advertised among women, few of whom access antenatal care in Ethiopia. Also reported to be problematic was the recommendation that HIV-positive women avoid breastfeeding, given the limited availability and high cost of infant feeding formula as well as the social stigma of “not” breastfeeding. Providers reported strongly advising women to not breastfeed but spoke about how many women did so against their wishes in order to protect their confidentiality within the community.

> “If my wife and I say we have planned to have a child, I can only imagine what the social pressure would be like. If they once know that my wife is not breast-feeding, they will start murmuring and gossiping. Thus the community awareness on this should be raised.” – Male partner, 32 yrs old, 3 children) P23: eth.com.fgd.males1.txt G.7. (32, SC, 8TH, 3).

> “What people think is that a mother who does not feed breast milk to her baby is HIV positive.” – Provider [P 1: eth.pro1.idi]

Also noted by policy influentials and providers was the need to continue to expand on all the elements of PMTCT, particularly the inclusion of more RH services such as FP and STI prevention and greater community support for women who have children and to also encourage other women to get tested.

> “I have given birth to three children. The first two died and the third child that is alive now is HIV positive. All this happened before I knew that I have HIV. My neighbours knew all this but are very supportive. Later they heard about the presence of treatment that prevents the transmission of the virus from mother to child, they encouraged me to have a baby. They worry a lot about me passing away with out replacing my self because they know that my son is HIV positive.” Woman, 27 years old, 3 children) P27: eth.com.fgd2.women24-44.txt R5: (40, M, SC, 7TH, 3)

IEC, Counselling and Psychosocial Support:
Almost no IEC materials were noted with a focus on the SRH services available to meet the needs of HIV-positive women and as noted, the quality of counselling for those accessing services was also reported to be poor or lacking. Some providers and women spoke about the impact of select media efforts to promote VCT as part of antenatal care. Most women and men reported preferring information obtained from reliable sources such as providers and community leaders to mass media. Women and men spoke about getting a great deal of information on family planning and health living as well as psychosocial support from community outreach visitors to *idirs* and *kebeles* (villages).

Almost all respondents reported the need for information at the service delivery and community level. Considering issues of literacy and socio-cultural and stigma around HIV, many respondents felt that information needed to rely more on outreach and less on print and media campaigns. Some felt that information to sensitize the community was strongly needed, but that more detailed information and psychosocial support was critical for women and men living with HIV/AIDS. Women and providers also reiterated that messages must be carefully crafted to not only target women, who are already blame and burdened for the epidemic, but that they should focus on behaviour change for both men and women. Women and male partners also noted that discussion of sexuality, which were commonly lacking, need to be integrated into community discourse and child education to help prevent the spread of the virus and recognize the SRH needs and reproductive rights of those living with the virus. Community members commonly said that persons who were living with the virus were the most appropriate peers to provide outreach and the psychosocial support needed to overcome the tremendous stigma and discrimination further exacerbated by poverty, and gender inequality, while providing employment opportunities for those in need. It was also felt that information and education without the necessary psychosocial support would not be adequate to allow women to incorporate this new knowledge.

> “To strengthen all services it will be helpful if health institutions train women living with the virus to use them as community workers.”—Woman 20 yrs old, 2 children [P25: eth.com.fgd1.women18-25.txt G.6. (20, M, SC, 6th, 2)]
>
> “Although women must get the information I don't think teaching women alone is enough. Almost all women are under the control of men. So even if we teach women the husband can force her to have sex despite her interest. We know that in this country women can't refuse to have sex if their husbands want to. So we need to involve men as well so men need to know about family planning.” Woman 35 years old, 3 children P27: eth.com.fgd2.women24-44.txt R2: (35, W, SC, 12TH, 3)
>
> “A number of people are entering in to risky situations not only due to lack of knowledge but because of so many reasons like financial problems or religious influence. There has to be an enabling environment for people to practice what they learn.” Woman, 30 yrs old, no children {P26: eth.com.fgd1.women25-55.txt G.6. (30, U, SC, 12th, O)}
>
> {We need to give} repeated education about HIV transmission & encouraging open discussion in sex related issues. If we support HIV-positive people we can break the silence.”—Woman, 30 yrs old, 1 child. {P26: eth.com.fgd1.women25-55.txt G.4. (30, W, SC 9th, 0)}

Policy and Programmatic Priorities and Needs:

Given recent evidence of the potential magnitude of the HIV epidemic in Ethiopia and its continuing high maternal mortality rate, policy influentials reported that issues related to SRH were increasingly becoming a priority in the public health policy and programmes discourse. Many policy 'influentials' spoke about the fact that the priority within HIV continues to be prevention or “control” of the disease rather than human and individual rights and needs. As such, a few said that dialogue about the SRH needs of HIV-positive individuals was one that they had never considered or heard discussed in policy meetings.

> “I have never heard an event on sexual and reproductive health needs of woman and adolescent girls living with the virus. I have never heard of panel discussions or others event in these issues. So this looks for me a new issue and specifically on reproductive health I have never seen.” Policy influential [P15: eth.pol2.idi]

> “Religious leaders, politicians, women's organizations, international NGOs, medical organizations, professional organizations [should be involved]. The health policy is old and has not been revised. The HIV policy was designed in 1998 and HIV/AIDS policy is part of the health policy.….When the policy was formulated there were no organizations strongly involved in gender issues; there were no strong female focused GO's or NGO's. Even in governmental institutions there were no such structures. Now there are NGOs working with women and HIV/AIDS. If all these institutions get a chance to be incorporated as stakeholders, I believe that it would make a very good contribution in improving the HIV policy.”—Policy influential [P20: eth.pol7.idi]

Despite improvements in recent years in HIV prevention programmes, many felt that there was a tremendous gap between needs and the existing capacity of services. To address these gaps, some providers and policy influentials felt that SRH services for HIV-positive women need to be integrated into the scope of HIV prevention, gender issues, and RH, but that this would require the collaboration of multiple bodies and organizations responsible for these areas to drive policy.

> “I think [RH services] should be integrated and also require the participation of the governmental, non-governmental and also private sectors. The government is not in a position to satisfy the need since these services are quite of wide range. Therefore, the reproductive services should be given in all health institutions to those who want to utilize the services so that they can be accessible to the community.” Provider [P10: eth.pro9]

> “The reproductive health community in principle believes that there is no integration on reproductive health thematic areas. As a result of this there is a problem in utilizing the limited resources that we have. Following this since the focus has been on HIV prevention there is failure in addressing the sexual and reproductive needs of people living with the virus and recognizing the long term impact of such approach. The failure to recognize this is not however at all levels. …………… The problem in integrating the activities is with the donors. They

> scrutinize the fund in to HIV, MCH and family planning. Even condom supply is divided in to family planning supply and HIV prevention supply. It is not only integrating both programmes but we also need to know how the programmes can be integrated in a way that the integration will not affect the effectiveness of both programmes but will enable them to be more effective" – Policy influential [P16: eth.pol3 }

Few felt that there would be any strong opposition to addressing the SRH needs of HIV-positive women and adolescents. Some felt that some community leaders and providers might be reluctant to support these issues with a focus on reproductive rights, including the right to bear children for those living with HIV. Faith based opposition to discussion of contraceptive use, including the promotion of condom use, was also mentioned.

A few policy influentials spoke about the need to look at all the missed opportunities for meeting women's SRH needs within the context of existing services. One policy influential felt that research, such as this qualitative study, was essential to understating the root causes of service gaps and advocating for change. Others felt that the most critical issue that should be addressed was increasing access to services thru expansion, community outreach, and training of providers to improve their knowledge and reduce stigma and discrimination experienced by those seeking care.

> "This is not to say advocacy is not important. It is rather to say advocacy alone is not enough and upgrading the knowledge and skill of the service providers is equally important." – Policy influential [P16: eth.pol3.idi]
>
> "If the service is available, the quality of the service provided, which includes the availability of different methods and the knowledge of the service provider, will have influence, but more than that the stigma free-approach of the service providers and their willingness to listen and give the necessary information that put their HIV status into consideration and leaving the decision to women and adolescents living with the virus is the main one. But when I say this I don't mean the professionals shouldn't put their medical knowledge in the decision making process."—Policy influential [P21: eth.pol8.idi]

Finally, several respondents felt that the capacity of communities and community organizations had not been adequately tapped into on many of these issues. Numerous policy influentials reiterated the importance of the collective roles and responsibilities of the different groups serving the needs of the community, while some reiterated that change will not be likely in the absence of community members, including HIV-positive persons advocating for their reproductive rights in a way that drives policy change, funding, and improved services and interventions.

> "So this issue starting from the policy it should be reorganized. Is there a resource mobilizing, and implementing, the institutions which are responsible to implement it are in place, these questions are very important. So to implement this policy, we have to concentrate on ownership, have different organizations could come together to work, but the ownership should be left to public." – Policy influential [P18: eth.pol5.idi]

> "If we look into the HIV/AIDS activities until now we have been doing what we can afford but the question is are these interventions planned based on the communities demand? Are we giving priority to the community needs? Are the interventions based on the community priority needs? This question has not been answered. We didn't put the communities' capacity into consideration but we need community interventions. Do the existing structures really go to the grass root level? Do we have organizations that are community based organizations that are very close to the community and share the community problem? So if we want to bring about change we must move [community] organizations that have roots in the community. We have been working in a top to down way and that is problematic. For me these community organizations are in the best position to expand the interventions including those related to the sexual and reproductive health needs of adolescents and women living with the virus." Policy influential [P20: eth.pol7.idi]

D. KEY FINDINGS: The UKRAINE

Sexual and Reproductive Health Intentions and Reproductive Rights: When asked who makes decisions about family size and fertility, most HIV-positive women and male partners of HIV-positive women felt that it was women or both partners in the couple. They also cited overwhelming consensus that the ideal family size included 2 children, with many noting a preference for one child of each gender. A few of the women interviewed in The Ukraine did not have any children.

Similar to Brazil and Ethiopia, many HIV-positive women and male partners said that despite the cultural importance of parenthood and childbearing, they had decided to limit or not have additional children due to their HIV infection. Reasons for compromising their ideal family size usually related to concerns about giving birth to an HIV-positive child, fear of community discrimination against them and their children, and concerns about not being able to support and raise the child due to economic and health reasons. Another reason women and male partners avoided having children were the strict instructions and expectations of providers and society that they should not become pregnant or give birth. A few said that they wanted to have a child eventually but were waiting for the right partner, marriage, or change in their economic situation before doing so.

> “I don't know to what extent medicine can guarantee an HIV-positive woman the birth of a healthy child. I think and common sense says that it's better not have children till the time, when medicine guarantees 100% a child who is not infected.” – Male partner, 28 yrs old, no children [P 1: ukr.com1.idi.malepartner3-20.txt]

> “One day I came to the gynaecologist for a medical examination. I was pregnant and they said that the child would be HIV-positive and that an abortion had to be done….This is connected with the fact that they don't want to see HIV-positive people, and they forbid HIV-positive to deliver.” –Woman, 20 years old, no children [P10: ukr.com11.idi.woman20S0.txt]

Providers and policy influentials had mixed ideas about women making their own reproductive health choices, including the right bear children. Most admitted that HIV-positive women and couples were until very recently strongly discouraged from becoming pregnant and having children due the risk of vertical transmission. Yet, several felt that this attitude was beginning to change due to advances in PMTCT interventions. Nonetheless, it was still felt that women should not make any decisions about pregnancy or fertility without the approval of providers who were best equipped to determine the clinical appropriateness of her becoming pregnant. Simultaneously, provider admitted that most women did not consult them when they wanted to become pregnant.

> “If a woman strives to have a baby, we explain her, what consequences can take place during pregnancy. We don't even try to dissuade her.”-- Provider P31: ukr.pro9.idi.oks4-06.txt

> “Some people think that everybody, every HIV-positive woman has the right to be a mother. And she has the right to decide if the child will live or not. It's a pity, there are many people who think that HIV-infection is indication that this woman has no right to have children.”—Policy influential [P35: ukr.pol2.idi.oks2-23.txt]

> “I believe that if she has done everything necessary to deliver a healthy baby, it must be understood in society. Of course, there is a percentage that will condemn her. But in principle, everybody has the right to be a mother.”–Provider [P24: ukr.pro2.idi.oks2-14.txt]

Matters of sexuality were reported to be much more complicated than for HIV-negative women for whom sexual relationships and bearing children were not considered a taboo. Women and male partners, many of whom rarely disclosed status to family and community, talked about feeling marginalized and how by disclosing their status and continuing to have sexual relationships they would be even more marginalized by society, which already labels them as irresponsible or out to infect others.

> **“**HIV-positive people are still considered to be outcasts of society…….all these drug users, sex business workers, punks, people with tattoos.”—Woman, 32 yrs old, no children [P12: ukr.com13.idi.woman32H0.txt - 12:7]

Women spoke about how they also struggled with issues of sexuality and sexual relationships with partners. Many reported feelings of guilt over having sexual desire, worried about infecting their partner, but many preferred to delay telling their sexual partners or hiding their status out of fear of their reaction and potential judgments and abandonment. Several women and some partners said that had withheld telling their sexual partners about their HIV status but always suggested but did not insist on condom use, particularly with non principle partners. Many of the women who had informed partners said they had not delayed getting tested due to lack of perception of risk and preference of not knowing their HIV status.

> “[I didn’t tell him because] I don't want him to leave me……..This disease is shameful. Only sex workers and drug users are infected. We never took drugs or anything ... He'll tell me ‘you have AIDS.’ So I don’t tell him. If he found out, I would tell him that it was he who infected me. I don't know.” –Woman, 32 yrs old, no children [P12: ukr.com13.idi.woman32H0.txt}

> “When I suggested to him... that he should also go get tested, at first he agreed, then later said that he would not do it because he didn't want to. I asked him why he didn't want to even though in principle I am not obliged to ask him. He told me that if he found out he merely wouldn't know how to live with it. He is satisfied with not knowing.” – Woman, 30 yrs old, 1 child [P21: ukr.com23.idi.woman30S1.txt]

Quality of Existing Services:

SRH services such as antenatal care, STI treatment, post-partum care, family planning services and abortion were in principle available at no cost in public hospitals and health centres for all women, including HIV-positive women if they wished to access them. There was one main HIV/AIDS clinic for Donetsk, commonly cited as the most comprehensive clinical care setting for HIV-positive individuals and offering some SRH services for those living with HIV. Voluntary testing and counselling was also available throughout the region, however other SRH services were reported to be very limited outside of Donetsk city.

Where services were available, women and male partners said that they rarely accessed them, except for emergency cases due to their experiences with discrimination and poor treatment by medical staff as well as issues of confidentiality and cost of services. In the Ukraine, there is a law criminalizing the non-disclosure of HIV status when seeking medical care, however, some women reported that they usually tried to avoid disclosing their status to avoid stigma and discrimination. Few women and male partners knew what services were offered or where, relying heavily on the guidance and counselling provided by NGOs when they needed care. A few women said that they had one specific provider from which they had received adequate care and to whom they returned for all subsequent medical needs.

> "Their attitudes towards those who are HIV-positive must be changed and then, maybe, people will come to see the doctor more often." – Woman, 20 yrs old, no children [P10: ukr.com11.idi.woman20S0.txt]
>
> "The problem is not what [services] they need. The problem is that they don't use them. There are many services offered by non-governmental organizations, but they don't use them, because there are no trustful relations. There are no mechanisms for attracting women to the services. That's why I think it's very important for women to ask for help, to educate medical nurses to be tolerant towards HIV-positive women; HIV-positive women should not be discriminated against, there must be no stigma. As the experience shows, peer education work is very useful. An HIV-positive woman who has a positive experience with services or help can share it with other HIV-positive women."— Policy influential [P32: ukr.pol1.idi.oks2-17.txt]
>
> "[An HIV-positive woman needs] all services……..I don't differ from other women who are not positive. Well, there is the virus in my blood, well, what to do? I have all the same rights as someone who is healthy." Woman, 36 yrs old, 3 children [P 9: ukr.com10.idi.woman36S3.txt]
>
> "They simply are afraid of coming to see a doctor because they are not well treated. They are discriminated, against, stigmatize and once more I'd like to speak about women-drug-users. Recently we have begun to work with the department for drug-users at the regional hospital. Our work showed that we must work with this group of people." – Policy influential P32: ukr.pol1.idi.oks2-17.txt

Providers interviewed commonly alluded to the risks of caring for HIV-positive persons and suggested a lack of practice of universal precautions by their strong support for the law criminalizing non-disclosure of HIV status. Some women said that providers' attitudes very much reflected this fear and stigma.

> "Patients, due to the law, must not create situations where they can transmit their infection. It means that if she visits the gynaecologist; she is obliged to tell the gynaecologist to put on two pairs of gloves.

> But how much she should say about her infection, it's already the weakness of the legislation." –Provider [P23: ukr.pro1.idi.oks2-11.txt]

> "According to our law on HIV prevention, there is criminal responsibility for transmission of HIV to another. It isn't written there that they obliged to tell doctors as a warning. My duty is to inform a patient that he/she has HIV and that person's duty to sign a paper acknowledging that he received this information from me and that he accepts any criminal responsibility. Well, it should be understood that he is obliged to warn sexual partner, medical workers." -- Provider [P27: ukr.pro5.idi.oks2-25.txt - 27:12]

> "Doctors start up when you come to the reception…..It would be very good, if there was a hospital for HIV-positive persons. You could go to any doctor and do not think that someone will kick you out or put on an extra pair of gloves." – Woman, 28 yrs old, no children P15: ukr.com17.idi.woman28S0.txt

> "Well, everybody is subconsciously afraid of being infected in the process of any procedure. It really should not be criticized because it is the elementary instinct of self-preservation and it is appropriate for doctors to fear as with any other person. But on the other hand, we doctors we have to provide adequate care, independent of diseases, confessions, political convictions, etc."—Provider [P24: ukr.pro2.idi.oks2-14.txt]

Women also reported that they were often mistrustful of the information given to them by providers, feeling that they rarely received all the necessary information about their rights and services. This was also noted by a few policy influentials and providers who discussed services in terms of women's rights.

> "I simply think that if you come to see a gynaecologist you must be fully informed by a doctor, because as a rule, women don't hurry to go there. And when they go, they feel too shy, they are afraid to ask questions, and they are generally afraid to lie on the gynaecological exam table. And as a rule, they go there in any extreme cases, if they fall ill, or suspect that she is pregnant. I think that the medical competence of our physicians is high but their ability to interact with patients is poor. Sometimes they push people aside to discourage them from coming back. And with that they merely won't go in general anywhere, until maybe somebody says that somebody went somewhere where she paid and received normal information that she wasn't discriminated against, insulted, she was listened to, and she in principle received, what she wanted." –Woman, 30 yrs old, 1 child [P21: ukr.com23.idi.woman30S1.txt]

> “Honestly speaking the majority of HIV-positive women know very little about what services exist and where they can receive them. Because from the start a woman signs a written declaration where it is written that she must not infect anybody and that she is criminally responsible for infecting another person but I don't believe that anybody ever gives her information that if she has duties the she also has rights.” – Policy influential [P42: ukr.pol9.idi.oks3-18.txt]

> “I think that the first reason why women don’t seek care is there is no information, no information on what is necessary for them to do in the sphere of reproductive health. She doesn't know what may be necessary. Maybe then she would come for counselling but she doesn't know if she needs it or not.” – Policy influential [P34: ukr.pol11.idi.oks3-21.txt]

Additionally, policy influentials spoke about the desire to have integrated services given how infrequently women accessed care. Some women mentioned preference for having centralized services, while other said they did not want to access care at centres dedicated for HIV-positive individuals due to confidentiality concerns. Moreover, women reiterated that how and where the services were offered were secondary to how they were treated by providers.

> “My opinion is that [specialized care], it makes no difference. I don't really want to go to the doctors even in specialized [HIV/AIDS] Centre. Although they treat people well, they treat people well from their medical point of view. There, any diagnosis comes out and is thrown out at you; it bangs you in the head………….There is no humane attitude [towards patients]. After visiting a doctor I need half a day or the whole day to come to collect myself psychologically. I try to rarely visit.” – Woman, 34 yrs old one child [P19: ukr.com21.idi.woman34H1.txt]

Several women spoke about wanting to receive services from other HIV-positive individuals or providers or from those who at least understood the comprehensive needs of those living with HIV and could provide humane treatment. The attitudes of some providers suggested a lack of interest and limited capacity to offer integrated SRH services without additional training.

> “I never treat sexually transmitted diseases. I can't give literate information concerning contraceptive preparations except the barrier ones as I have already mentioned. I counsel them on where they can go.” Provider [P27: ukr.pro5.idi.oks2-25.txt]

Family Planning, including dual protection:

Women and male partners’ knowledge of family planning methods was very limited, usually focusing on condoms and sometimes oral contraceptive pills. Women also reported the cost of contraceptive methods as a major barrier to use. The main method used by several women and male partners to prevent unwanted pregnancy was condoms. However, few reported consistent condom use.

While providers and policymakers in principle understood the advantage of two methods for dual protection, instead of using condoms alone for dual protection, few actually recommended it or discussed it. The major reason why dual methods were not recommended by providers were misconceptions about appropriateness of use of methods in conjunction with condoms and the cost of methods, since only condoms are offered free of charge. Some providers believed that any method could be used by the women for family planning, but many said that they insisted on condoms only for women with sero-discordant partners.

> “Clients of our project are women using drugs and so it is best if they use condoms. Those girls who have enough money, they can afford pharmaceuticals, contraceptives. Our patients can't afford the cheapest pills”—Policy influential P38: ukr.pol5.idi.oks3-14.txt
>
> “Well, of course, I would like to know the state of a husband and it would also depend on her health. We would then search for appropriate methods. If the sexual partner isn't infected then of course condoms must be used.”-- Provider P24: ukr.pro2.idi.oks2-14.txt
>
> “If her husband isn't HIV-positive, than a condom is prescribed until the time she wants to conceive. If both partners are HIV-positive and she doesn't take ARV preparations, then in principle, she can use oral contraceptives, but of course under the monitoring. If she takes ARV preparations, oral contraceptives are prohibited.” – Provider [P23: ukr.pro1.idi.oks2-11.txt]

Women’s responses suggested an understanding of the advantages of condom use but difficulty implementing regular use for safer sex for a range of reasons, including lack of understanding of personal risk and risk to one’s partner during unprotected sex, a preference for sexual activity without condoms, association of condoms with mistrust, and lack of ability or desire to broach issues of sexuality, even with steady partners. For most women, condom use was something they considered mostly out of need to protect their partners or to prevent pregnancy, and often the decision to use or not use condoms was thus left to male partners. Few women insisted on condom use with partners and male partners said that while they disliked condoms they were more willing to use them if the woman was insistent or for pregnancy prevention.

> Yes, [my partner] supports [condom use], but, let's say that he thinks that what will be, will be. It means if we were in a situation where I hadn't already had a child or if one of us had sexual relations on the

> side, then he thinks that condoms should be used. But we are husband and wife, he thinks ... he doesn't want to use condoms"—Woman 26 yrs old, 1 child [P20: ukr.com22.idi.woman26H1.txt
>
> "They know about condoms, but there are those who are lazy and don't protect themselves. May be there are some other factors. Some are afraid to offend the partner that their partner could leave. It seems to me that everybody knows about [condoms]." – Provider P25: ukr.pro3.idi.oks2
>
> "It's a pity, but women use contraceptives not to protect themselves, but a partner."—Policy influential P32: ukr.pol1.idi.oks2-17.txt

Sexually Transmitted Infections:
It was reported that women were routinely screened for syphilis as part of antenatal care and for other STIs upon the presentation of symptoms based on the syndromic approach. There were no integrated protocols suggesting routine screening for HIV-positive women and men in the absence of symptoms. Men and women often associated STIs with symptoms and spoke about waiting for symptoms to go away or self treatment for STIs as preferable options to having to access health services for treatment.

Breast and cervical cancer:
Given that women rarely accessed services other than for ambulatory reasons, none mentioned having been screened for cervical or breast cancer and few even knew of pap smears or self breast examinations. Only one woman knew about self breast examinations as taught by her mother. The few that had heard of cervical or breast cancer, associated prevention of both cancers with early detection upon the appearance of symptoms, but were generally unfamiliar with the symptoms. When told of the importance of screening, many women said that they did not know that they should be seeking the services or where they could go to get them.

Unintended Pregnancies:
Abortion legislation in the Ukraine gives women the legal choice of termination of pregnancy. Abortion services are generally provided using dilatation and curettage as part of inpatient services at most public facilities with gynaecology departments. Some of the woman interviewed reported having had an abortion before knowing their HIV status and a few after. Some said that they were advised by providers to have an abortion when they tested HIV positive. Providers and policy influentials reported that this was commonly the case prior to the introduction of PMTCT services but that attitudes had also changed on this issue to allow women the choice. One policy influentials cited statistics based on a recent survey conducted of HIV-positive women, which suggested that the pressure on women to have abortions was high.

> “[According to our recent study] out of 40 women interviewed, 18 said they experienced pressure from a medical worker, meaning pressure to interrupt their pregnancy.” – Policy influential [P34: ukr.pol11.idi.oks3-21.txt]

> “Even the doctors sometimes think that if a woman is HIV-positive she must interrupt pregnancy. Only by changing the global outlook of people will we change attitudes towards HIV-positive women in our society.”—Policy influential P36: ukr.pol3.idi.oks3-2.txt

Maternity Care Including PMTCT Services:
Policymakers and providers commonly referred to the introduction and expansion of PMTCT services as the reference point for when SRH services first became available to women. Few women and male partners interviewed had recent experiences with PMTCT services, but those who had delivered in tertiary facilities reported mostly negative experiences with the care and treatment received, mostly due to stigma and discrimination encountered. This was particularly the case with women who presented for delivery and were given a rapid test that showed that they were seropositive. As with other services, women’s experiences with PMTCT services suggested that informed choice was lacking. For example, a few of the women talked about how they were either told not to breastfeed at all or asked whether they were planning on breastfeeding but without adequate and quality counselling to help them make informed choices.

> “I know that HIV transmission from a mother to child is and will be a very real problem. In practice this programme on prevention of HIV transmission from a mother to a child proved that... in practice we can show that the level of children infected has decreased from 25% to 7.5%. In the future, if we include more pregnant women and give more treatment, there is no shortage of treatment; we will be able to achieve the level of developed countries that is 2-3%. [PMTCT]It is one of our priority strategies.” – Policy influential P35: ukr.pol2.idi.oks2-23.txt

> “They called me in and asked me if I'd planned to breastfeed or not….I said I didn’t know, what do you advise me? They said: "It is your decision!" And so I breast-fed. As far as I know, that breast-feeding is, in general, better. ….. And before it was considered better to breast-feed that artificial feeding….They said that “it is your choice”. They spoke about percentages. Let's say, such percent are infected, such are not. And told it is my decision. So I chose but did I understand? I really did not understand.” – Woman, 36 yrs old, one child [P11: ukr.com12.idi.woman36H0.txt]

Most women had limited knowledge about PMTCT programmes based on information obtained from other women who used the service or local NGOs providing outreach and information. There was strong desire for more information about the possibility and risks of pregnancy for HIV-positive women and strong desire that the information also be made public to counter the negative public views about HIV-positive women making their own reproductive health choices.

> “There needs to be information…Our society is against HIV-positive people. HIV-positive people are afraid of everything. Two or 3 years ago my wife got pregnant and we thought that we wanted to leave a child but at that time we didn't know all these measures of preventing transmission from mother to a child. We were 100% certain that the child would also be born HIV-positive. That's why we decided to have an abortion.” – Male partner, 32 yrs old, 1 child [P 6: ukr.com6.idi.malepartner5unknown.txt]

> “The more there is information that HIV-positive women can deliver a healthy baby, the more supportive people have become. Till the end of 90s there was an opinion... I encountered it with my acquaintances... to prohibit HIV-positive women from delivering. But now it's changing.”— Policy influential P32: ukr.pol1.idi.oks2-17.txt

Infertility Services:[*]

When asked about infertility services or technologies that could help sero-discordant couples have children, all women and male partners said that either such services were not available to them or not affordable. One private facility in Donetsk which specializes in infertility services reported that it required mandatory HIV testing for all couples seeking fertility assistance. It was mentioned that while the clinic had tested a handful of individuals who were found to be positive, few of them came back for their results. While it had not offered HIV-positive individuals infertility care or assisted reproduction for sero-discordant couples, there was willingness noted to explore offering services to such individuals at a potentially lower cost.

IEC, Counselling and Psychosocial Support:

Almost all respondents commented that existing IEC materials and information about SRH did not adequately meet the needs of HIV-positive individuals. Respondents echoed the need for better community information on HIV prevention and more targeted information and counselling to HIV-positive women and male partners.

> “There are few materials. There are booklets which were put together for HIV-positive pregnant women, they are used to provide support and explain that she can deliver a healthy baby. But for HIV-positive women in general there is nothing.” --Provider [P23: ukr.pro1.idi.oks2-11.txt]

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[*] Infertility services were not included in Brazil and Ethiopia because of their limited availability.

> “The existing media campaign meets the needs of entire population: It is about HIV prevention. It's useless for HIV-positive women.”—Provider [P31: ukr.pro9.idi.oks4-06.txt]

Some policy influentials felt that to contribute to positive behaviour changes in SRH, messages need to be consistent and reflect existing and accessible services in order to create motivation for behaviour change. HIV-positive women and male partners reiterated that the messenger is equally if not more important than how the message is positioned and could easily make individuals mistrustful of the information received and promote further stigma and discrimination.

> “Simply receiving information won’t make one motivated. Motivation appears then when one generation tells another generation. That is at home a girl is told that [condom use] is needed; it is necessary. That it is all for your future health. It should come from schools, anywhere else, anywhere else. If everything is united, then there is a system of giving knowledge and the same information. After receiving information once, it seems to me, motivation doesn't occur.”—Policy influential [P37: ukr.pol4.idi.oks3-9.txt]

> “They receive information from medical workers who are HIV-positive too. That's because such patients prefer to communicate with people like them. Nobody understands the problem better than those who have it. It's a pity, but I think that from mass media they receive nothing.” --Policy influential [P35: ukr.pol2.idi.oks2-23.txt]

> “Information can discourage people from [seeking services]. First because these services are expensive; second, the information given is not professional, not correct, and not well thought out. It is once more the question of professionalism. It's better to do nothing then to do something poorly.”—Male Partner, 28 yrs old, 1 child [P 1: ukr.com1.idi.malepartner3-20.txt]

NGOs and PLWH networks were generally trusted by women and male partners and considered an integral part of the psychosocial support process. Individuals working with youth or women and men recovering from substance abuse commonly spoke about how they struggled to meet the basic survivorship needs of individuals and could not offer many of the clinical services needed. While it was felt that NGOs should continue to provide a great deal of these psychosocial services, it was clear to many providers and policy influentials that some of that work needed to be incorporated into medical institutions and programmes to increase utilization. Providers and policy influentials noted the need to train providers to recognize the importance of counselling and psychosocial support and provide whatever could be offered as part of existing services, particularly for youth and women in difficult situations such as those overcoming drug use, violence and/or abandonment.

Policy Priorities and Programmatic Needs:

In Donetsk, where HIV infection rates are high compared to other regions of The Ukraine, general issues of HIV prevention were considered to be the top priority by many policy influential. The vast majority of policy influentials saw no strong opposition to the idea of making reproductive health services more accessible to HIV positive women and adolescent girls some suggested that faith based organizations and leaders who refuse to acknowledge HIV as a problem may not support efforts.

Otherwise, it was believe that the lack of focus on this issue was the result of a lack of resources and donor support, poor coordination of services, and lack of advocacy for a rights-based approach to SRH services for HIV-positive women and youth. A few policy influentials lamented the fact that national policies and bodies commissioned organizations to monitor the HIV situation but did little to react to the needs identified. Some policy influentials said that voices of women as users of the services continued to be absent on the policy level as they were when HIV policy was written into the health policy. Some providers added the needs of providers as another key component.

> “In my point of view, it is the fault of our state and legislative bodies that put together documents but don't involve HIV-positive people in the process. Mainly we use the norms, which the Public Health Ministry issues. These are guidance or let us assume the decrees of Cabinet of Ministers….At the heart of the matter, our opinions are seldom sought. That is they have issued circular letters and then you just have to implement it and very often we receive different norms and documents which contradict one another.” – Policy influential [P35: ukr.pol2.idi.oks2-23.txt]

One key policy influential added that while issues of reproductive rights and services for women were important, it was important that the focus continue to be on women’s rights and needs and that for example, it was equally important to consider how services can work towards preventing HIV infection in pregnant women who are initially HIV-negative but become infected during their pregnancy due to increased risks associated with that period.

> “It is a very big risk group. We tried to count how many women were infected before the delivery. We investigated it. Because at the registration she is negative, at the examination on the 38, 34, 36th week she is HIV-positive. I cannot tell that there are many such women, but they are. It is maybe about 5-10%.” – Policy influential [P35: ukr.pol2.idi.oks2-23.txt]

To address the gaps in services, some providers and policy influentials felt that integration of SRH services into existing public and NGO services would be a key step requiring the collaboration of multiple bodies and organizations responsible for women's issues, health, and reproductive and human rights to drive policy and develop and action plan.

In addition to the need for broader IEC at the community level and more targeted counselling and psychosocial support for women and male partners, training of health personnel, legislation acknowledging the rights of women, and reduced cost and physical distance to services were all noted as important strategies for addressing the unmet SRH needs of HIV-positive women and adolescent girls.

IV. DISCUSSION

The findings from this study are similar to those that have been noted in previous social science and programmatic research into the SRH needs of women, including HIV-positive women. The results should be interpreted with caution in developing a national action plan to address the comprehensive needs of HIV-positive women, since the primary intent of this research was to explore a broad range of issues that need to be addressed. Nonetheless, the study identified key programmatic and policy gaps related to SRH that should be considered, including:

- a limited range of SRH services for HIV-positive women;
- a lack of access to appropriate and timely care for HIV-positive women;
- a lack of integration or linkages among SRH services within the health system and among sectors;
- poor quality information and counselling;
- stigmatizing and discriminatory attitudes and practices;
- poor monitoring of quality of care and lack of accountability for system deficiencies;
- inadequate policies, legislation, guidelines and norms;
- and arguably, limited commitment, resources and political will to introduce changes at this stage of the epidemic in the absence of advocacy.

Sexual and Reproductive Health Intentions and Rights:

Respondents in all three countries had varying views about both ideal family size and those responsible for decisions about fertility and reproduction. The belief that HIV-positive women had to inevitably compromise their desired SRH intentions due to their infection, however, was consistent and an issue that came up in almost every respondent interview and focus group discussion. HIV-positive women and adolescents, as well as male partners, reported feelings of fear, guilt and shame about sexuality and child-bearing. Many said they felt that they had to be content with already living children. Stigma associated with being an HIV-positive parent, the risks of vertical transmission, uncertainty about one's own health, and economic reasons were the most common reasons cited for avoidance of childbearing. In sero-discordant couples, views towards reproduction and sexuality varied, with slightly more favourable views toward childbearing.

Men and women reported that generally providers were more tolerant of women who accessed services while initially pregnant, but that they did not embrace the reproductive rights of HIV-positive women to choose to have more children. To some extent, Brazilian women reported that certain providers were open to discussing fertility and family planning as options for HIV-positive persons, a welcome change considering that it was not so long ago that HIV-positive women, including some who participated in the research, were pressured into sterilizations. In both the Ukraine and Ethiopia, HIV-positive women and male partners reported that they continued to be strongly discouraged from childbearing, but were not counselled about how to avoid unintended pregnancy. In the Ukraine, several women reported being pressured into terminating pregnancy. Not surprisingly, women who desired to get pregnant rarely shared their reproductive intentions with providers.

Providers had mixed views about HIV-positive women having the ability to make informed choices about their sexuality and fertility. The responses of most suggested theoretical broad support for the rights and choices of women living with HIV, including their right to make informed choices about sexuality and fertility. But, when it came to actual practices, providers reported mixed views about their patients exercising those rights. Several providers, particularly in the Ukraine and Ethiopia, said they were hesitant to give any information about fertility as an option, or even discuss family planning, so as to not encourage women to consider pregnancy. Providers in all settings admitted to being uncomfortable dealing with issues of sexuality in the context of SRH counselling, particularly for HIV-positive persons.

Equally difficult for many HIV positive women and girls and male partners of HIV-positive women were discussions of sexuality and HIV with sexual partners and family. Most women and adolescent girls in relationships said that they were open about their serostatus with their partner, yet some women, particularly in The Ukraine, chose not to disclose their status at all with sexual partners.

Quality of SRH Services:

The range, type and quality of SRH services were reported to be uneven among sites, geographic regions and countries. Where available, specialized services for people living with HIV, such as PMTCT programmes, were generally preferred by women and adolescents due to their reported greater sensitivity to issues of confidentiality and care. Women, providers and policy influentials, particularly those in Brazil, commented on the recent improvements of care for HIV-positive women in the context of PMTCT, but insisted that there remained large gaps due to limited availability of services, lack of integration, poor provider attitudes, and low community awareness. Even specialized services were reported to have inadequacies with respect to their ability to address the broad range of SRH services desired by women and adolescents.

Women's ability to make informed choices was usually considered a major quality of care issue. Adolescent girls interviewed in Brazil also emphasized the problematic lack of control over their health decisions and the prioritization of parental need and desires over those of HIV-positive minors. Many women, particularly those in the Ukraine and Ethiopia, reported avoiding health services altogether except for emergencies or serious health conditions mostly due to negative experiences with health services. Women in all three countries cited stigma and discrimination among other barriers to care, including long wait times, geographic distance to facilities, poor provider attitudes, and badly organized services. These issues, along with the lack of integration of services, were reported to be problematic in all three settings and recognized by providers and policy influentials alike. Women were also concerned about the limitations of certain providers to address their holistic health needs and the lack of consideration of their psychosocial needs.

Family Planning Including Dual Protection:

There were tremendous gaps in the knowledge of women, male partners, and providers about appropriate family planning methods for HIV-positive women. Condoms and abstinence were the most commonly discussed and primarily cited appropriate methods in all three countries regardless of women's reproductive health intentions and concerns. Some women knew of pills and injectables, which many providers did not offer (IUDs were also not offered by many providers) due to mostly erroneous beliefs that these methods were contraindicated for HIV-positive women. Tubal ligation, while initially the most common method recommended to women living with HIV for birth limiting in Brazil, was reported to be less stressed in other settings, as well as now in Brazil since the introduction of effective PMTCT programmes. Providers and policy influentials in all three settings revealed concerns about informed choice of family planning methods discouraging condom use. (i.e. cause women to use condoms less or stop using them entirely). Simultaneously, many providers and policy influentials stressed their concern that despite their insistence on condom use, HIV-positive individuals rarely used condoms, a reality confirmed by HIV-positive individuals interviewed.

The dual protection advantages of condoms were recognized by almost all respondents in the three settings, yet few providers stated that they emphasized this aspect in counselling, except in the case of sero-discordant couples. Some providers and policy influentials stated that they recognized the difficulty of condom use for women, yet many failed to integrate this understanding into helping women develop the necessary skills to negotiate use. Women and adolescent girls living with HIV noted a plethora of challenges stemming from gender power inequalities and social taboos about sexuality that made negotiating condom use very difficult. Further hindering condom use were women's negative feelings about being HIV-positive, dependence on male partners, and fear of potential consequences of suggesting condom use, including partner suspicion about fidelity, violence, and abandonment by partners. Many HIV-positive women and male partners, including sero-discordant male partners understood the risks of infection or re-infection during unprotected intercourse, but repeatedly reiterated their strong dislike of condoms due to hindrance of sexual pleasure, inability to negotiate or introduce them into the relationship, or lack of perception of personal risk of infection.

Prevention and Treatment of STIs, Breast and Cervical Cancer:

Counselling about STI risk factors and the importance of timely detection and treatment in HIV-positive persons was rarely discussed by most providers interviewed, few of whom offered routine asymptomatic screening of HIV-positive individuals in the three countries. Pregnant women were reported to be routinely screened for syphilis as part of antenatal care; otherwise, the syndromic approach to STI diagnosis and treatment was commonly used with referral to STI centres for treatment in many cases. Not surprising, knowledge of STIs and risk factors were low among HIV-positive women, adolescent girls and male partners; all generally associated STIs with symptoms, including discharge, pain, or bleeding. The asymptomatic nature of many STIs was rarely recognized and women rarely sought testing or treatment in the absence of symptoms. Women and male partners in Ethiopia, and a few in Brazil, spoke about self treatment or use of herbs prescribed by traditional healers based on symptoms.

Few providers acknowledged the importance of screening for cervical dysplasia and breast cancer for women and adolescents who were HIV-positive. Only a few women across all countries recalled having received routine breast examinations during annual gynaecological exams; few knew about the importance or techniques of self breast examinations. In Brazil and The Ukraine, some women who had suffered from breast cancer spoke about the difficulty they had getting timely and appropriate care due to complicated referral systems.

Very few HIV-positive women (mostly in Brazil) knew if they had ever been screened for cervical cancer. In fact, almost all women and male partners commonly equated cancer prevention with early diagnosis of cancer. Few women grasped the importance of asymptomatic screening for preventing cervical cancer or its relationship to HIV infection. Some women spoke about their fears of vaginal examinations as reasons why they did not present for gynaecological visits. Women and adolescent girls previously diagnosed with cervical dysplasia spoke about their difficulty in getting appointments for cervical biopsies and treatment.

Safe Abortion Services:

Abortion is highly restricted in both Brazil and Ethiopia, but available upon demand in the Ukraine. As such, safe abortion services were rare in the first two countries and none of the providers interviewed performed the procedures; a few did provide postabortion care. In both Brazil and Ethiopia, respondents, particularly women and male partners, spoke about the problem of lack of access to abortion services, what some described as a dilemma for HIV-positive women who were discouraged from becoming pregnant yet simultaneously given no safe options for terminating unintended pregnancy. Several respondents commented on the toll of unsafe abortion, including incorrect, illicit use of misoprostol and unsafe abortions performed by village healers in Ethiopia.

At least one woman in all three countries commented about the discrimination by health workers who would not treat an incomplete abortion or provide an abortion to HIV-positive women due to fear of infection. On the other hand some women in The Ukraine reported having been advised or pressured by providers to have an abortion due to their HIV status. Contrary to the experience of women, providers and policy influentials felt the attitudes towards abortions were shifting as HIV-positive women were gradually being given their rightful choices to carry pregnancies to term, or have an abortion, due to improvements in PMTCT services and improvement in antenatal counselling.

Maternity Care Including PMTCT:

Antenatal services, including VCT and PMTCT were available in specialized centres in the urban areas where the research was conducted. In all three settings, respondents reported that improvements in PMTCT had revolutionized care for HIV-positive mothers and their children, albeit gaps remained and there was a continued need for improvement. For many women and adolescents, advances in PMTCT not only offered the opportunity to deliver a potentially healthy child but allowed women to access services that were better than those previously received before becoming pregnant. Others reported that while PMTCT services had set the standard for care for women living with HIV, they had nonetheless inadequately addressed the range of SRH needs of women in a holistic fashion due to a primary focus on protecting the child and not enough on the needs and rights of mothers. Additionally these services had failed to engage the community to address the psychosocial needs of pregnant women living with HIV. The inability to breastfeed was noted to be one of the most difficult and problematic elements of PMTCT for many women, who commented on the psychosocial difficulty and stigma faced when not breastfeeding.

Some providers and policy influentials reported concern that PMTCT programmes received the bulk of funding and support, while other areas of maternity care and SRH services remained neglected.

IEC, Counselling and Psychosocial Support:

Respondents in all three countries strongly noted the gap in IEC, counselling and psychosocial support as one of the main barriers to women accessing services and being able to make informed choices about their SRH needs.

HIV prevention campaigns were the focus of most IEC materials and counselling messages in the three countries. Many of the media campaigns were criticized for being either too general, inadequate for promoting positive behaviour change, and/or reinforcing of stereotypes and fears about HIV-positive persons. In Brazil, there were many periodic campaigns, usually around world AIDS day or Carnival and some print materials aimed at HIV-positive persons, but few relevant to SRH services and needs. In both The Ukraine and Ethiopia there were even fewer IEC resources available and those that were available were usually only distributed through primary PLWH networks or NGOs responsible for providing care and support for HIV-positive persons.

Many providers caring for HIV-positive women were aware of the psychosocial needs of these women, but reported limited capacity and time to address them, leaving the bulk of this responsibility to PLWH networks and other community and faith-based organizations. Community members and peers, as well providers, were reported to be the most trusted and preferred sources of information for women, adolescents and male partners. As such, all respondents spoke about the need to “humanize” health services to promote the holistic needs and concerns of women, with an emphasis on continuing to link existing, usually overburdened health services, with community-based groups and associations that can provide the necessary care and support to women and adolescents.

Policy Priorities and Programmatic Needs:

The gaps between available services and women’s rights and SRH needs suggested a need for shifts in national health policy priorities and programmatic needs, paralleling stronger international commitment and local advocacy for the rights of women and adolescents living with HIV. Many of the persons living with HIV interviewed were very skeptical and disheartened by the slow pace of change in policies and services. Several women and male partners, particularly in the Ukraine and Ethiopia reported feeling abandoned by their communities and government in their daily battles to overcome stigma and discrimination. A large number of providers and policy influentials interviewed admitted that they had not contemplated issues of rights of HIV-positive women and adolescent girls until this research, but articulated the strong need for improvements in care, suggesting multi-sectoral collaboration, research, and advocacy as the way to begin to shift political will and policies. Others felt that this would only come with international commitment and financial resources to promote both the rights and holistic SRH needs of women and adolescent girls.

Limitations:

The researchers recognize that this qualitative study meant to explore the SRH needs of HIV-positive women and adolescent girls has several limitations that should be kept in mind when interpreting the findings. As with most qualitative research, the findings of this study are not intended for generalization or to be viewed as representative of the perspectives and perceptions of any particular group or population, nor are they intended as an evaluation of quality and availability of SRH services in the three countries. In addition, the policy and service delivery level respondents in the research were generally individuals close to issues of HIV and AIDS and thus may reflect a deeper knowledge and commitment to these issues than the average provider. Likewise, the voluntary nature of this research meant that individuals who consented to participation may have been more supportive of the issues and more vested in changes to the status quo. For HIV-positive women and adolescent girls and their male partners, identification and sampling was based on their participation in PLWH networks who may, by affiliation, be a group that is more familiar with or more likely to utilize services, although some findings suggest otherwise.

Recommendations for Further Research:

The findings from this study suggest a number of issues or areas for further research including:

- Operations research to address the various programmatic and policy gaps highlighted in this report, such as testing ways to improve access to and quality of SRH services for HIV-positive women and adolescent girls; approaches for reducing stigma and discrimination; and models of service delivery that link SRH and HIV programmes through integrated approaches.
- Exploring approaches to making PMTCT services more widely available by integrating PMTCT into health services in rural areas and outside of specialty research centres in urban areas.
- Assessing missed opportunities for meeting women’s SRH needs within the context of existing services in order to understand the root causes of service gaps, including replication of qualitative studies similar to this one in other settings.
- Conducting research similar to the current study in rural areas may yield different results and raise additional issues since most of the respondents in this study were based in primarily urban regions.
- Additional research is needed to clarify issues around hormonal contraceptive use by HIV-positive women, as current gaps in the science make providers more likely to promote only condoms.
- Investigating ways that providers, social workers, peer educators, and others working with HIV-positive women and adolescent girls can help them develop the necessary skills to negotiate condom use.
- Exploring ways to make the voices of HIV-positive women and adolescent girls, as well as their advocates (e.g. health providers, feminists, PLWH groups), heard on the issue of rights and needs of HIV-positive women.

Conclusions:
This research identified some interesting trends across the three countries and some issues unique to each setting that need to be considered in strategic planning efforts to improve HIV-positive women’s and adolescent girl’s access and utilization of SRH services. This research indicates more advocacy is required, including engagement of policy influentials, to address lack of awareness, and policy and programmatic gaps, regarding the rights and health needs of HIV-positive women and adolescent girls. There is unevenness of health providers’ understanding of SRH of women living with HIV and an inability to respond to their rights. It is also essential to ensure that HIV-positive women and adolescent girls are aware of their rights so they can exercise them.

This qualitative study will contribute to a rights-based framework on policy, health systems, and advocacy guidance on SRH for PLWH, especially women and adolescent girls currently under development with key partners. SRH services for PLWH must be accessible, non-discriminatory, compassionate, of high quality and rights-based.