Responding to changes in HIV policy: Updating and enhancing the Families Matter! curriculum

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Responding to Changes in HIV Policy: Updating and Enhancing the Families Matter! Curriculum

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Abstract

Objectives—The past decade has seen changes in US HIV policy in sub-Saharan Africa in response to a new Administration and far-reaching technical, scientific and programmatic developments. These include: dramatically increased access to life-saving ART and related services; the roll-out of voluntary medical male circumcision; and growing sensitivity to gender-based violence, including child sexual abuse, and to its role in increasing vulnerability to HIV. The Families Matter! Program (FMP) is an intervention for parents and caregivers of 9–12 year-olds that promotes effective parent-child communication about sexuality and sexual risk reduction. FMP was adapted from a US evidence-based intervention in 2003–4 and is now implemented in eight African countries. In 2012–13, the FMP curriculum was updated and enhanced to respond to new US Government priorities.

Methods—Enhancements to the curriculum drew on the results of Violence Against Children surveys, on a review of existing literature, on feedback from the field on the existing curriculum, and on stories written by young people across Africa for scriptwriting competitions.

Results—We updated FMP with scientific content and stronger linkages to services. We also intensified our focus on structural determinants of risk. This contextualisation of sexual risk-taking within structural constraints led us to place greater emphasis on gendered vulnerability and the diverse pressures children face, and to intensify our situation-based pedagogical approach, drawing on the authentic youth-authored narratives.

Conclusion—We describe these changes as an illustration of and source of insight into much-needed programmatic adaptation in response to evolving HIV policy.

Keywords
Policy; Preadolescence; Parenting; Gender-Based Violence; Child Sexual Abuse

Introduction

Health education curricula need to be regularly updated to respond to evolving policy, science, and services. While guidelines have been proposed for adapting programmes to new

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populations and/or cultural contexts (for example, McKleroy et al., 2006), less attention has been devoted to adapting curricula over time to ensure they remain optimally effective and responsive to evolving needs.

The past decade has seen unprecedented scientific, technical and programmatic advances in the response to the HIV epidemic in sub-Saharan Africa. These include new evidence for the effectiveness of anti-retroviral therapy (ART) (Cohen et al., 2011) and voluntary medical male circumcision (VMMC) (Reed et al., 2012) as prevention strategies; dramatically increased access to ART, VMMC, HIV testing and counseling ( HTC), and related services; and growing awareness of the scale of gender-based violence (GBV), including child sexual abuse (CSA), and of its role in increasing vulnerability to HIV infection (Andersson et al., 2008). In addition, Violence Against Children (VAC) surveys have documented the extent of physical, sexual and emotional violence suffered by children, demonstrating the need both to prevent it and to mitigate its impacts (e.g., UNICEF Tanzania et al., 2011; Reza et al., 2007). It is also evident that adolescents and young people are becoming a more prominent sub-group among those living with HIV as antiretroviral therapy (ART) allows greater numbers of those infected perinatally to reach adolescence while new adolescent infections remain high: disparities in health outcomes between adult and adolescent populations highlight the need to prioritise young people living with HIV and better integrate their needs into HIV programmes (UNAIDS, 2013; WHO, 2013).

US government priorities for HIV and AIDS have evolved in response to these developments and with the change in Administration. On the occasion of World AIDS Day 2011, the then US Secretary of State Hilary Clinton presented her vision for an AIDS-free generation (Clinton, 2011), advocating a combination prevention approach – bringing together mutually reinforcing biomedical, behavioural, and structural interventions – characterised by a science-driven and integrative perspective. While focusing on ending mother-to-child transmission of HIV, expanding VMMC, and scaling up treatment for people living with HIV, she acknowledged that these approaches work best when combined with condoms, HTC, and strong health systems, and that they rely on institutional and social changes like ending stigma and GBV.

The Families Matter! Program (FMP) is an intervention for parents and caregivers of 9–12 year-olds that promotes positive parenting practices and effective parent-child communication about sexuality and sexual risk reduction (Miller et al., 2013). The ultimate goal of FMP is the reduction of sexual risk behaviours among adolescents, including delayed onset of sexual debut. Parents are in a unique position to reach youth early, often, and comprehensively with information and support related to sex, risk, and responsible sexual decision-making skills. The purpose of FMP is to give parents and caregivers the knowledge, skills, comfort, and confidence to discuss sex-related issues with their children. FMP is unique in that it does not dictate what parents should say to their children but instead guides them in defining the values and messages they want to convey.

FMP was adapted for use in Kenya from the US evidence-based intervention, the Parents Matter! Program (PMP) (Forehand et al., 2007) in 2003–4, during the early years of the President’s Emergency Plan for AIDS Relief (PEPFAR), the U.S. Government initiative to
help save the lives of those suffering from HIV and AIDS around the world. FMP has gradually expanded throughout sub-Saharan Africa as countries that experience high burdens of HIV among youth and are funded by PEPFAR have requested the programme. As of August 2014, CDC/PEPFAR supports the cultural and linguistic adaptation, implementation, and scale-up of FMP in Kenya, Tanzania, Cote d’Ivoire, South Africa, Zambia, Botswana, Mozambique, and Zimbabwe. The programme has been delivered to over 400,000 families and is currently available in fifteen languages. Despite high demand and evidence of effectiveness (Vandenhoudt et al., 2010), the curriculum was updated and enhanced in 2012–13, almost a decade after it was first developed, in order to align with priority US Government goals for HIV and to respond to the findings of the VAC studies.

The speed and scale of change in HIV policy is such that it can be challenging for programmes to keep pace. However, it is critical that information delivered by programmes remains up-to-date and that messaging is consistent across programmes. We describe the changes we have made to FMP as an illustration of programmatic adaptation in response to evolving HIV policy. We hope that our experiences will be instructive to others as they seek to enhance, update and adapt their HIV-related programmes in response to a rapidly changing environment.

**Background**

FMP is a community-based, group-level intervention delivered by two certified local facilitators (one male, one female) through a series of weekly three-hour sessions using participatory adult learning techniques. Verbal and visual instruction techniques are incorporated in the curriculum to meet auditory and visual learning preferences. A number of different strategies and learning methods are used, including: group interaction activities such as proverb/poster discussions, large group discussions, brainstorming, role-plays (between adult participants, and between parents/caregivers and their child), songs and ice-breakers; narratives in an audio format that are played on a battery-operated CD player in low-resource rural areas and follow-up discussions; mini-lectures; participant handouts; and homework assignments.

In light of the cultural diversity of sub-Saharan Africa, and of individual sub-Saharan countries, the FMP curriculum is adapted – both culturally and linguistically – to specific regions following local community needs assessment and pre-testing. As such, the reference curriculum described here addresses normative and structural barriers to sexual health that are likely to be at play across a large proportion of sub-Saharan Africa. This manuscript focuses on changes made to align the FMP curriculum with US HIV policy. The enhanced curriculum will, however, be adapted to reflect changes in local policies, priorities and other in-country issues – including context-specific cultural norms – prior to local roll-out.

At their broadest, definitions of GBV embrace unequal power relations between men and women; at their most specific, they focus on physical and sexual violence, usually against women (United States Agency for International Development, 2012). The newly-revised FMP curriculum seeks to promote reflection, dialogue and action across the broad spectrum of GBV issues – from gender norms and the role they play in HIV-related risk to CSA.
Methods

Enhancements drew on findings from: the VAC studies; a review of qualitative literature on youth, HIV and sexuality in sub-Saharan Africa and of interventions that contextualise HIV within sexual culture and gender norms (see Greig et al., 2008: for an overview); and feedback on the existing FMP curriculum from partners in the field. This feedback was provided in the context of regular technical assistance provided by CDC to the implementing partners, including at annual site visits and through structured reporting. This incorporates formal feedback provided by beneficiaries to implementing partners as part of scheduled programme evaluation activities and informal feedback provided to CDC by project beneficiaries in the context of site visits in certain locations. The programme’s interactive curriculum incorporates skills-building role-play exercises and audio resources, which present everyday situations seen through the eyes of children, young people and parents. Enhancement of these resources and activities drew on stories written by young people across Africa for the Global Dialogues/Scenarios from Africa scriptwriting competitions (Global Dialogues, 2015; Winskell and Enger, 2014).

Intervention Updates and Enhancements

Alignment with US Government priorities and, most specifically, with the integrative approach advocated in the 2011 World AIDS Day goals provided a welcome opportunity to make the interconnected changes described below. These include content updates, strategies to increase access to HIV services, increased focus on contextual determinants, and a related emphasis on a situation-based pedagogical approach.

Updated Content and Linkages to Care

The FMP curriculum was updated to include the latest available information on HIV, ART, HTC and VMMC and related services. In addition, place-holders were added for active linkage to those services via context-specific lists of community health resources, additional information, and maps to facilities which will be added when the curriculum is adapted to specific settings. In addition to abstinence, safer sex practices, and contraception, it also addresses a broader range of sexual and reproductive health issues than before, including sexually transmitted infections (STIs), stigma and disclosure. The enhanced curriculum specifically addresses disclosure to a new generation of young people living with HIV, many of whom were infected peri-natally and have been able to reach preadolescence thanks to increased access to ART, but who may not have been informed of their sero-status.

Sexuality

The enhanced curriculum focuses less on risk behaviours and more on the broader context of sex, including relationships and gender norms (Aggleton, 2004). While the curriculum provides detailed information – about reproductive anatomy, contraception, etc. – to increase parents’ and caregivers’ comfort in talking about sex, it also empowers low-literacy parents to draw on their own life experiences to guide their children.

Parents are encouraged to talk with their children about sexuality and personal safety; to use parenting skills, like supervision, to protect their children; and to help their children
recognise and, through role-play, prepare for situations that may put them at risk. Audio narratives model good parent-child communication around gender and sexuality, often through the eyes of a child. A boy, for example, narrates how his parents dispel myths about male inability to control sexual urges, while a girl describes how her parents alert her to the fact that boys and men are likely to behave differently towards her as her body changes.

**Focus on Gendered Vulnerability**

Throughout the curriculum, difficult topics are addressed in culturally sensitive ways, with a view to promoting lasting change and avoiding confrontation that can be counterproductive. Thus, for example, rather than condemning early and cross-generational marriage and female genital cutting, it invites participants to identify these as traditional practices which perpetuate unequal gender norms and increase the vulnerability of young women.

Parents are prompted to consider and question gendered differences in children’s life goals, in social (and parental) expectations, and in their vulnerability to HIV. They are encouraged to empathise with the experiences of 9–12 year-old males and females so that they can relate to the physical, emotional and social changes their preadolescents are going through and the need to provide guidance and support to children at this important age. This includes preparing children not only for physical changes, but also for their struggles to understand how to respond to social expectations of what it means to be a man or a woman in their community.

The enhanced curriculum places increased emphasis on the various gendered pressures – structural, normative, group and interpersonal – that young people face and the factors that, in the absence of guidance and support, can constrain their ability to make healthy choices. For example, audio narratives and role-plays address the pressures to conform to norms of masculinity, which may include alcohol and drugs in the context of male group socialising, pressure to be sexually aggressive or else suffer social exclusion, and embarrassment to seek out information about sex.

**Pressures Children Face**

Where the earlier curriculum focused above all on peer pressure, the enhanced curriculum incorporates skills-building role-play exercises and audio resources that address a range of pressures children face, including peer, partner and adult pressure to have sex. In the context of pressures both young women and young men face from sexual partners to have sex when they are not ready or prepared to do so safely, FMP presents the model of a healthy relationship (Haffner, 1995). In this model, based on mutual respect and communication, partners are able to refuse sex or accept if a partner refuses to have sex with them, and plan ahead to avoid pregnancy and STI/HIV. FMP introduces parents to the risks for sexual violence that their children face, both as potential victims and potential perpetrators and exhorts parents to discuss consent with their male and female children.

The curriculum addresses pressures young people face from adults to have sex in exchange for goods, money, grades at school, or employment, and the limits this gendered power dynamic places on their ability to negotiate condom use (Luke, 2003). It addresses how social norms increase the risk that children, especially girls, face from adults who pressure
them to have sex. It also encourages parents to reflect on what they can do to help change these norms, traditions and expectations so that intergenerational sex is no longer accepted in their community.

**Situation-based Approach**

The new curriculum frames parents’ role as providing guidance and support to allow children to recognise and – through cognitive and behavioural rehearsal – prepare for situations children may face that may put them at risk so they can make healthy choices. The curriculum aims to increase parents’ and children’s understanding of the contextual reality of risk. The 7-session enhanced curriculum incorporates 28 audio narratives, and 9 role-play exercises. In audio recordings, for example, female characters describe the temptations of taking a ‘sugar daddy’ in terms of their desire to avoid the pity of peers or be the last girl in school without a cell phone. The curriculum also encourages parents to identify with some of the factors that might make a relationship with an older male attractive. Role-plays seek to prepare them for risk situations. For example

- What would you do if… you are walking through the neighborhood when the tailor calls you over and whispers in your ear that he’s made you a beautiful dress: why don’t you come into his workshop and try it on?
- What would you do if… the neighbor who has been kindly paying your school fees since your father lost his job asks you to come over to his house that evening?

**Child Sexual Abuse**

FMP has been identified as a valuable platform for addressing CSA because the programme is widely accepted within communities and teaches parenting skills that closely map onto protective factors identified in previous studies on CSA (Thomas et al., 2003). By the time participants have reached the sixth session on CSA, they are already well primed on the gender power dynamics and age-related hierarchies that increase opportunities for CSA. The session aims to raise parents’ awareness about CSA, increase their understanding of their role in preventing it and, if necessary, in responding to it. They learn to apply the main parenting strategies of FMP to protecting their children from CSA: they develop skills to talk with their child about CSA and situations that could put them at risk for CSA; identify actions that can be taken within the family or household and within the community to protect children from CSA; and learn to recognise the signs of potential or actual abuse. Acknowledging that parents may not be able to stop an adult from forcing their child to have sex, the session addresses actions parents can take at the family and community level in the event that their child or a child in their community is sexually abused, including supporting their child and using services (e.g. for post-exposure prophylaxis, emergency contraception and mental health) if/where they exist.

An extended audio narrative about a girl’s abuse by her uncle help parents understand the progressive and insidious nature of some abuse. Interactive discussion following the audio recording seeks to help parents understand that, while the child might be able to understand the risk that she could face from a stranger when she is out alone after dark, it is much more difficult for her - based on her limited life experience - to understand risk within her own
home or in other places where she normally feels safe. It drives home the message that children do not suddenly become adults when they reach puberty and that they need adult help in order to understand situations that can put them at risk. The audio narrative culminates in a central prevention message: the No Secrets, No Threats, No Gifts rule. It also seeks to communicate to parents the strategies abusers may use to: manipulate their victims; shift the blame for the abuse to the victim; and manufacture a sense of complicity or responsibility on the part of the victim which militates against timely disclosure.

**Adolescents Living with HIV**

An optional Session 7 has been prepared for family members of adolescents living with HIV and individuals who are likely to come into contact with them by virtue of the roles they play within the community. Living with HIV amplifies the need for guidance in navigating the physiological, social and behavioural changes and challenges of adolescence (Hodgson et al., 2012). This session seeks to increase awareness and understanding of the specific challenges facing adolescents living with HIV – including stigma and mental health, disclosure of the child’s status to the child and disclosure by the child to others, ART adherence and other aspects of self-care, and sex and romantic relationships – and to help family and community members strengthen their skills to provide adolescents living with HIV with effective guidance and support on these issues.

**Discussion**

Against the background of changes in US HIV policy in sub-Saharan Africa and far-reaching developments in the response to the epidemic, we updated FMP with scientific content and stronger linkages to services. We also intensified our focus on structural determinants of risk, which led us to strengthen our situation-based pedagogical approach, drawing on authentic youth-authored narratives.

**Updated Content & Linkages to Care**

Content updates were dictated by scientific, technical and programmatic developments, but also reflected historical phenomena. It was, for example, necessary to address the needs of adolescents living with HIV, many of whom belong to a unique historical cohort, who did not benefit from PMTCT, but who have been able to reach adolescence thanks to increased access to ART.

Amidst growing recognition of the mental health and other burdens associated with managing menstruation in contexts where resources and support are lacking (McMahon et al., 2011), the enhanced curriculum promotes parent-child communication and support around this issue. FMP is also pursuing partnership with the Puberty Books Project to provide additional resources for parents and their pre-adolescent female and male children (Sommer, 2011).

Under its first authorisation (2004–8), PEPFAR was criticised for neglecting the GBV-HIV link (Ghanotakis et al., 2009). Following its 2008 reauthorisation and amidst mounting evidence that GBV is both a cause and consequence of HIV infection, PEPFAR sought to integrate GBV prevention and response in its programmes (Khan, 2011), leading us to
address the HIV-GBV link more directly throughout FMP. This in turn prompted us to enhance the curriculum’s approach to gender and sexuality.

**Sexuality, Gendered vulnerability & pressures, and Situation-Based Approach**

Over the past decade, a wellness-focused approach to sexual health – advocated in the 1994 Programme of Action of the International Conference on Population and Development (UNFPA, 1994) – has become increasingly mainstream. This is facilitated by increased access to ART, which has permitted a shift away from the pathologisation of sex and allowed HIV to be more integrated within sexual and reproductive health. This development is accompanied by willingness to acknowledge the complex factors that shape human sexual behaviour. In addition, it reflects a more general shift away from an ethos of solely individual responsibility for risk behaviours to greater recognition of the structural, normative and power-related constraints on individual agency, and growing recognition of how social inequalities influence risk.

These developments, marking a shift from a frame of risk to one of vulnerability (Aggleton, 2004), are accompanied by increased focus on the contextual reality of sexual behaviour and the social construction of gender and sexual norms. The enhanced FMP curriculum both reflects these perspectives and encourages parents to challenge community norms that provide opportunities for GBV and thereby to promote a more enabling environment for their children to be sexually healthy.

This focus on promoting greater contextual understanding of preadolescents’ vulnerability is allied with a more situation-based skills-building approach, aligned with principles of Social Cognitive Theory (Bandura, 1977). Narrative audios and role-playing exercises play a central role here. When developing health education materials, it is customary to collect formative data by means of focus group discussions and in-depth interviews. However, transcripts from this kind of data collection are not always easily translated into curricular materials. The authentic stories written by young Africans provided by Global Dialogues/Scenarios from Africa lend themselves more readily to adaptation into health education materials, which are well-suited for low-literacy adult learners.

**CSA**

As a parenting intervention that addresses CSA within the context of broader parent-child communication around sexuality and sexual risk-reduction, FMP is conceived as a valuable component of multi-level efforts to prevent and respond to CSA in sub-Saharan Africa. As throughout the enhanced curriculum, the sixth session seeks to interface with local community mechanisms and to promote linkages to local and national-level CSA-related services, including medical and mental health services. In addition, the curriculum encourages parents to engage their community around CSA. Hence, FMP is sensitive to the structural dynamics that underlie CSA in sub-Saharan Africa and the broad-based mobilisation that is necessary to its prevention (WHO Regional Committee for Africa, 2004). While poverty, patriarchal norms and impunity for perpetrators represent major obstacles to CSA prevention, we contend that parents can be empowered to protect their children, to respond in the event of abuse, and to advocate for change.
Future Steps

Several long-term evaluations of FMP are planned for 2014–15. Additionally, at the request of implementing partner organisations in several FMP countries, the programme is currently being adapted to expand beyond the pre-risk arena to address the parent-child communication needs of parents of adolescents ages 13–18. An outcome evaluation is being planned to assess the impact of the CSA-focused session on parents’ awareness of CSA and its associated risks. The evaluation will also examine the intervention’s impact on parents’ self-efficacy to open a dialogue with their children about CSA, help protect their child from CSA, and respond in the event that their child experiences or has experienced CSA.

Conclusion

Health education curricula need to be updated and enhanced to respond to evolving policy, science, and services. This is particularly true in the rapidly changing field of HIV. We have updated FMP with scientific content, linkages to improve access to services, and intensified focus on structural determinants of risk, in particular GBV. This contextualisation of sexual risk-taking within structural constraints has led us to place greater emphasis on gendered vulnerability and the diverse pressures children face, and to intensify our situation-based pedagogical approach, drawing on authentic youth-authored narratives. Our experiences are shared as a source of reference and lessons learned. We hope they will be of value to practitioners working in HIV and in sexual and reproductive health more generally as they seek to ensure their curricula remain optimally effective and responsive to evolving needs and priorities.

Acknowledgments

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References


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<td><strong>1: Introduction to FMP and Steps to Understanding Your Child</strong></td>
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<td><strong>Session 1 Goals:</strong></td>
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<tr>
<td>• To provide group members with an understanding of the purpose and goals of the Families Matter! Program</td>
<td>• To provide parents and caregivers with an understanding of the purpose and goals of the Families Matter! Program</td>
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<tr>
<td>• To help the group get to know each other and develop a desire to continue to participate in the programme</td>
<td>• To increase parents’ and caregivers’ awareness of the situations their children face that may put them at risk and the important role they play in keeping their children safe and healthy.</td>
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<td>• To increase group members’ knowledge of adolescent development and how that may influence their child’s participation in safe and healthy behaviours</td>
<td>• To introduce parents and caregivers to the physical, emotional and social changes their pre-adolescents are going through and the need to provide guidance and support to children during this important period</td>
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<td>• To increase group members’ awareness that they, as parents, influence their children’s participation in healthy and safe behaviours</td>
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<td><strong>2. Good Parenting Skills</strong></td>
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<tr>
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<td>• To provide parents and caregivers with information and strategies to protect and guide their children through this important period</td>
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<td>• To make parents and caregivers more aware of the need for them to be sex educators for their children</td>
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<tr>
<td>• To make parents more aware of the need for them to be sex educators for their children</td>
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<td>• To help parents and caregivers to define their values about sex and to learn ways to communicate their values to their children</td>
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<td></td>
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<td>• To provide parents and caregivers with direct linkages to community health resources</td>
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<tr>
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<td>• To continue improving parents’ and caregivers’ comfort in discussing sex and sexuality with their child</td>
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<tr>
<td>• To help parents provide guidance to their children about peer pressure</td>
<td>• To give parents and caregivers an opportunity to work on their communication skills with their child</td>
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<tr>
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<tr>
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<td>• To raise parents’ and caregivers’ awareness about child sexual abuse</td>
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<td>• To increase parents’ and caregivers’ understanding of their role in preventing child sexual abuse</td>
<td>• To increase parents’ and caregivers’ understanding of their role in preventing child sexual abuse</td>
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<td>• To increase parents’ and caregivers’ awareness of their role in protecting and supporting their children when responding to child sexual abuse</td>
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<td>• To increase family and community members’ understanding of challenges facing adolescents living with HIV including those related to stigma, disclosure, adherence, and healthy relationships</td>
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<tr>
<td>• To help family and community members strengthen their skills to provide guidance and support to adolescents living with HIV around issues of stigma, disclosure, adherence, and healthy relationships</td>
<td>• To help family and community members strengthen their skills to provide guidance and support to adolescents living with HIV around issues of stigma, disclosure, adherence, and healthy relationships</td>
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<tr>
<td>• To provide family and community members with information about living with HIV, anti-retroviral therapy, and resources in their community to help adolescents living with HIV</td>
<td>• To provide family and community members with information about living with HIV, anti-retroviral therapy, and resources in their community to help adolescents living with HIV</td>
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