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*Mothers for the Future:*  
Piloting a Parenting Curriculum for Mothers Who Are Sex Workers  
in Cape Town, South Africa

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## ABSTRACT

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By Jennifer Lynn Holl

**Background:** The stigmatization and criminalization that often surround sex work leaves those in the industry vulnerable to human rights violations and increased health risks. The majority of programs and research related to sex workers focus on HIV prevention and treatment in this population. This, however, results in the primary healthcare, mental health and many psychosocial needs of sex workers going largely unaddressed. Few, if any, interventions targeting the specific needs of sex workers who are mothers are in existence. The *Mothers of the Future* curriculum seeks to address this gap within the South African context.

**Purpose:** The purpose of this special studies project is to assess strengths, weaknesses, and acceptability of the content and structure of the recently developed *Mothers for the Future* curriculum and to make programmatic improvements based on findings collected during the piloting of the curriculum. Program refinement is expected to improve facilitator training and future program delivery.

**Methods:** From June to August 2015, a program assessment of Mothers for the Future was conducted at SWEAT headquarters in Cape Town, South Africa. Seven sessions of the *Mothers for the Future* curriculum were pilot-tested over the course of a three-week workshop. Curriculum materials and program implementation were assessed through facilitator observations, pre- and post-test surveys, key-informant interviews and focus group discussions.

**Results:** Participants in this assessment demonstrated high levels of satisfaction with the program. During piloting, several themes speaking to the participants' overarching needs, values, and beliefs emerged. These themes include: support, respect, learning and education, self-esteem, and empowerment/self-efficacy. Participant feedback also revealed key areas for improvement of the curriculum. Revisions to the curriculum were made to reflect these findings, and broadly include restructuring of individual sessions, clarification of language and instruction, and the provision of supplemental information where gaps in content were indicated.

**Discussion:** As the first curriculum of its kind, *Mothers of the Future* is poised to become a model for future parenting interventions designed for sex workers. While setting-specific piloting and more rigorous evaluation of the curriculum and its long-term impact will be required to measure program effectiveness, preliminary results from this assessment are promising.

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I would like to acknowledge the hard work of Kate Nelson, without whom this project would not exist. I thank you for the development of the *Mothers for the Future* curriculum and for involving me in its evolution. I hope that this special studies project and the modifications made to the curriculum are in line with your original vision for this program. I also hope that through our combined efforts, we can make a valuable contribution to mothers who are sex workers and their families, both at SWEAT and beyond.

Last, but certainly not least, my heartfelt gratitude goes out to all of the mothers who allowed me to join their space and to lead them through the *Mothers for the Future* pilot workshop. I would like to thank you all for your commitment and for participating in the activities and providing the feedback enclosed in this special studies project that will serve to make this curriculum stronger. I hope that it becomes a tool that can be useful to mothers across South Africa, just as Dudu has envisioned, and that each of you can take great pride in knowing that you helped to create it. You truly are role models for the community and for the mothers of the future.

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# CHAPTER 1: INTRODUCTION

## INTRODUCTION AND RATIONALE

Though sex work is a large and pervasive global industry, it is also highly stigmatized and legally restricted in most settings. The criminalization, and further marginalization of sex workers through stigmatization, leaves those involved in the sex industry vulnerable to a number of human rights violations such as violence, harassment, and discrimination.[1] These experiences also create barriers to sex workers accessing legal, social, and health services.[1] Fear of repercussion in the forms of violence or imprisonment, and lack of protection under the law, may prevent sex workers from challenging such violations of their rights from coming forward to report wrongdoings against them.[2]

The UN and Amnesty International, among others, have issued statements calling for decriminalization of sex work in the name of health and human rights.[2, 3] Evidence suggests that in environments that are considered to be supportive of sex workers' rights, and which have limited legal restrictions, sex workers experience better health and economic outcomes, and even greater access to education for their children.[1, 2] Despite growing support for decriminalization from the international community over the past decade, sex work remains criminalized in many countries. South Africa, for example, is among the least supportive nations, fully criminalizing sex work under the Sexual Offences Act 23 of 1957. This law prohibits not only the selling or solicitation of sex in exchange for reward, but also makes it unlawful to benefit from earnings obtained through sex work, maintain a brothel, or allow sexual services to be procured on one's property.[4]



While there are some exemplary programs working to empower sex worker movements and others advocating for the decriminalization or legalization of sex work, outside of the arena of HIV prevention and treatment, literature on issues of importance to sex workers remains somewhat limited. In many contexts, sex workers are placed at higher risk for acquiring HIV infection. Estimates suggest that in low- and middle-income countries, female sex workers' risk of HIV infection is 13.5 times higher than that of the general female population.[5] In South Africa, where overall prevalence of HIV is 18.9%,[6] the additional risk for female sex workers is estimated to be 4.4 times greater than women who are not involved in sex work.[5] As such, HIV is certainly one area on which public health programs for sex workers should focus their efforts. However, the emphasis on their status as a key population in the HIV epidemic often leads to large gaps in programming that supports the psychosocial, occupational, and primary health needs of sex workers and their families. An estimated two-thirds of female sex workers in Sub-Saharan Africa are also mothers,[7, 8] suggesting there may be significant impact on the children of sex workers due to the risks of violence, discrimination and poor health indicators to which their mothers are exposed.

Recent estimations suggest there are between 131,000 and 182,000 sex workers living in South Africa.[9] In the Western Cape alone, figures range from 14,900 to 38,507.[10] A 2008 study estimated there to be roughly 1,200 sex workers working within Cape Town and its surrounds, however the 2013 size estimation suggests that the industry is much larger with between 5,000 and 7,500 sex workers in Cape Town.[10, 11] While these estimates include male (5%) and transgender sex workers (4%), a large majority of sex workers in South Africa are female. This estimate suggests that as many as 0.8% and 1.5% of the total female population of South Africa may be involved in sex work.[10] This is hardly an insignificant portion of the

population, and as such, allowing these barriers to accessing services to go unaddressed may have serious public health implications.

### ***Sex Worker Education and Advocacy Taskforce***

Sex Worker Education and Advocacy Taskforce (SWEAT) is one of the primary organizations working with sex workers in South Africa. Their vision is for there to be a “legal adult sex work industry where sex work is acknowledged as work, and where sex workers have a strong voice.”[12] SWEAT is headquartered in Cape Town, however they have chapters across South Africa. In addition to being staunch advocates for the decriminalization of sex work, SWEAT provides additional programming in three key areas: Advocacy and Networking, Research and Knowledge Management, and Outreach and Development. Advocacy efforts target the campaigns for decriminalization and policy reform and bringing awareness to and challenging human rights violations, while the research arm is involved with the promotion and compilation of studies and resources related to sex work and health and human rights interventions. Outreach and Development programs focus on providing educational and psychosocial support, in addition to linkage to health and legal services. In each of these program areas, SWEAT empowers sex workers by employing them in leadership roles, training peer educators, and involving them at every level of the organization and in decision-making roles. SWEAT maintains the philosophy that the key stakeholders and beneficiaries should, whenever possible, speak on their own behalf, and as such they work to build the capacity of sex workers to become effective communicators and to facilitate opportunities to interface with policymakers and stakeholders on the provincial and national levels.[12]

### ***Mothers For the Future***

A large part of the Outreach and Development arm of SWEAT's program consists of Creative Spaces and support groups, which meet weekly or bi-weekly. These groups provide safe spaces for sex workers to come together to learn about and/or discuss a wide range of topics. Creative Spaces are larger forums in which sex workers congregate in groups based on gender, while support groups typically accommodate smaller sub-groups of SWEAT service-users, such as those seeking support for adherence to their antiretroviral (ARV) medications, those who have issues with substance use, or those who are mothers. The mothers group, Mothers for the Future, is a relatively new group at SWEAT, introduced in 2014 to support the unique needs and vulnerabilities of sex workers in their roles as mothers.[13]

To bridge a prior gap in SWEAT programming, Rollins alum and previous Emory Global Health Institute (EGHI) award recipient, Kate Nelson, conducted a community needs assessment in June and July of 2014. The goal of this needs assessment was to develop a framework for the Mothers for the Future program, in addition to content tailored specifically for mothers who are sex workers. During that time, a preliminary course structure was developed with sessions based on themes arising during the needs assessment, including reproductive health, child safety, and financial planning, among others. The first iteration of the Mothers for the Future program, however, relied heavily on guest facilitators to deliver content over the 12-week program. During the pilot period (July to December 2014) the need for further curriculum development, facilitator instruction, and program structure were identified.[13] In order to address these limitations, Ms. Nelson developed the *Mothers for the Future* curriculum as a special studies project. This curriculum consisted of nine sessions ranging from two to three hours in length, complete with

facilitator instructions, resources, and materials to accompany each session, to support program delivery by SWEAT staff or in-house volunteers.

### **PROBLEM STATEMENT**

Many women who become sex workers are motivated to do so by economic need and in order to provide for their families.[8] Young women who enter the field of sex work are put at higher risk for STIs, unintended pregnancy, and violence among other adverse outcomes.[14, 15] They are also, however, more likely to “avoid healthcare for fear of being judged or stigmatized.”[16]

While healthcare is free and available at the government clinics in South Africa, it has been suggested that negative experiences and fear of stigmatization may act as significant deterrents to accessing services in a timely manner.[17] With an estimated 5,000-7,500 sex workers residing in Cape Town, low utilization of healthcare presents a noteworthy public health concern.[10] On a national scale, upwards of 182,000 sex workers may be left with the choice between free health care available in facilities in which they feel judged and discriminated against or paying for care at private facilities. While interactions are reported to be more positive at private facilities, costs may be prohibitive for many, potentially leading them to go without care. When access to maternal health care is hindered, it often places not only the mother, but also her children at risk.[18] This additional consideration of the impact on the children of sex workers presents an even greater concern, with the potential for lasting downstream, generational effects.

One possible consequence of these barriers to healthcare among sex workers who are mothers is a negative impact on maternal health outcomes. Although progress has been made in recent years, South Africa has a high Maternal Mortality Ratio (MMR) for a middle-income

country.[19] Utilization of maternal health services is quite high, however estimates may “hide variations in use by race, urban/rural residence and socioeconomic status.”[19] While the sex work industry is demographically quite diverse, many sex workers share characteristics that are often associated with lower healthcare utilization. According to a 2008 study, a large portion of street-based sex workers in Cape Town are women of color, many of whom come from poor backgrounds and have not completed high school.[11] Additionally, HIV and patient-oriented barriers such as delayed help-seeking and infrequent antenatal care (ANC) visits contribute significantly to maternal deaths in South Africa.[19] A 2008 National Committee on the Confidential Enquiry into Maternal Deaths report found the institutional MMR to be ten times higher among HIV-positive women than those who were HIV-negative.[19] Similarly, the report attributed 26.8% and 23.7% of maternal deaths to delayed care and insufficient ANC visits, respectively.[19] Coupled with high rates of HIV infection, it is possible that stigma and other barriers contribute to lower utilization among the sex worker population, increasing risk for sex workers and their children. As researchers Silal et al. propose, “in order to move towards the MDGs, it is essential to focus not simply on increasing maternal service coverage levels, but to address systematically all of the access constraints that pregnant women face.”[19, p.10] This is particularly true when addressing the unique health needs of population that has been historically stigmatized, such as sex workers in South Africa.

Apart from maternal health, there needs to be an emphasis on improving access to services ranging from non-judgmental HIV screening and treatment to primary health care. Enrollment in HIV care and services geared toward the Prevention of Mother to Child Transmission (PMTCT) must be accessible to ensure mothers remain healthy enough to care for their children and to continue working, and to reduce the number of children acquiring HIV

during pregnancy and childbirth. Greater attention to primary health care must also become a focal point, as the same acute and chronic conditions that affect the general population are of concern to sex workers. Chronic disease and mental health in particular may impact sex workers' ability to earn a living to support their families, and as such should take on a more prominent role in the discussion of sex worker health. This is imperative for the many sex workers who have little support from partners or family, as their children become even more vulnerable to effects of their mothers' health status.

### **STATEMENT OF PURPOSE**

The purpose of this special studies project is to assess strengths, weaknesses, and acceptability of the content and structure of the *Mothers for the Future* curriculum and to make programmatic improvements based on findings collected during the piloting of the curriculum materials. Refining the curriculum materials and processes will allow for greater ease in facilitator training and future program delivery. Additionally, the incorporation of participant feedback should allow SWEAT to maximize understanding, satisfaction, and knowledge gain among future recipients of the program. The development of an effective and user-friendly curriculum becomes increasingly important as SWEAT readies itself to take the Mothers for the Future program to scale across South Africa. The pilot program being implemented in Cape Town is intended to function as a model for the nation, and as such careful testing and fine-tuning of the curriculum in this stage will be essential in ensuring the success of this program expansion. Activities involved in this special studies project serve to meet several key objectives, outlined as follows:

**Objective 1:** Pilot and evaluate curriculum implementation in order to assess participant satisfaction and acceptability and to identify opportunities to improve program processes, structure, and content.

**Objective 2:** Revise curriculum materials based on findings identified through the evaluation process, thereby providing SWEAT with a refined product that is likely to produce high levels of participant engagement, satisfaction, and understanding.

**Objective 3:** Amend the 2015 curriculum with the addition of supplemental activities aimed to strengthen health literacy and patient self-advocacy for sex workers navigating local health services as members of a group that is often stigmatized and/or criminalized.

### **SIGNIFICANCE STATEMENT**

The implementation of curriculum improvements will provide SWEAT's mothers with a powerful tool that aims to build self-efficacy, and that will allow them to challenge barriers and further educate themselves on how best to maintain their own health and safety, as well as that of their children. The development of this curriculum and its validation and enhancement through this special studies project will also serve as a landmark endeavor in South Africa, which, if shared with SWEAT sites in each of the nation's provinces, as planned, has the potential to reach a substantial number of women and their families.

### **DEFINITION OF TERMS**

**(Commercial) sex industry:** The combined phenomenon of individuals, establishments, customs, and messages involved in commercial sex.[20, p. 2]

**Service user:** A sex worker who accesses the services and/or programming SWEAT provides.[13, p. 12]

**Sex work:** The provision of sexual services for money or goods.[20, p. 2]

**Sex worker:** Women, men and transgendered people who receive money or goods in exchange for sexual services, and who consciously define those activities as income generating even if they do not consider sex work as their occupation.[20, p. 2]

**ACRONYMS**

ANC	Antenatal Care
ART	Anti-Retroviral Therapy
ARV	Antiretroviral (medication)
EGHI	Emory Global Health Institute
FAS	Fetal Alcohol Syndrome
HIV	Human Immunodeficiency Virus
MDGs	Millennium Development Goals
MMR	Maternal Mortality Ratio
PEP/PrEP	Post-exposure prophylaxis/Pre-exposure prophylaxis (for HIV)
PMTCT	Prevention of Mother to Child Transmission of HIV
STI	Sexually Transmitted Infection
SWEAT	Sex Worker Education and Advocacy Taskforce
TB	Tuberculosis



## CHAPTER 2: REVIEW OF THE LITERATURE

In order to contextualize the experiences of mothers participating in the Mothers for the Future assessment and those who may benefit from its implementation in the future, a review of the literature was conducted. As stated previously, the great majority of academic literature on sex work is focused on HIV risk and prevention. However, many other factors impact the daily lives of women in the sex industry outside of this risk, including factors that might impact female sex workers' ability to parent. This review seeks to build upon previous efforts completed during the 2014 community needs assessment and subsequent special studies project completed by Ms. Nelson, and further explores topics that will be used to inform anticipated modifications to the *Mothers for the Future* curriculum.[13] To better understand selected experiences of female sex workers and how key issues might be addressed through SWEAT's programs, the present review of the literature investigates how sex workers who are mothers manage their dual identities, their experiences with occupational stigma, and the impacts of each on their access to health and social services. Additionally, community empowerment approaches for sex workers, patient self-advocacy, and curriculum development were explored in order to inform adaptations to the curriculum and to provide support for programmatic design choices.

### ***Sex Work and Motherhood*** *Work-related Stress*

Working parents often experience stresses related both parenting and their work lives. For sex workers, these stresses may be exacerbated as they also face fears of violence, harassment, and incarceration in many settings.[21] In addition, sex workers may experience mental distress regarding how family members, including their children, might be impacted if their involvement in sex work is discovered.[21] Sex workers in South Africa and beyond are

made more vulnerable to these risks due to the criminalized status of their work and the stigma that is often associated with sex work.[22] These stressors may be further intensified for street-based sex workers and those experiencing instable housing, limited access to health and social services, or grappling with substance abuse.[21, 23, 24]

### *Managing Dual Identities*

Findings from a qualitative study in the United Kingdom conducted by Dodsworth reinforce the unique challenges that sex workers may face in occupying their dual identities as working mothers.[25] Again, meeting the sometimes unattainable societal expectations of the “good mother” can be difficult for any working mother, however as sex workers, mothers may receive additional disapproval both for working outside of the home and for their involvement in work that is often viewed as illegitimate.[25] Applying Breakwell’s theory of the “threatened identity,” Dodsworth posits that the dissonance created by trying to fulfill the expectations of both mother and sex worker results in “threats” to each of these aspects of the woman’s identity.”[25] Similar to Sloss and Harper, Dodsworth believes reconciling these conflicting identities may be made more difficult for sex workers due to unique occupational risks, including stigmatization and criminalization.[21, 25] She also proposes that stress from these occupational risks, coupled with the challenges of parenting and the condemnation they face for not living up to the image of an ideal woman or mother, create psychosocial risks that may impact self-image and, potentially, parenting behaviors.[25] This study found that sex worker mothers largely fell into two groups – those who were able to maintain a positive self-image as a mother while working as a sex worker, and those who found these two identities to be somewhat incompatible.[25] Findings suggest that those in the first group sustained greater feelings of self-efficacy, agency and self-worth, which in turn allowed them to better cope with stigmatization

and gave them greater confidence in their ability as parents.[25] Alternatively, those in the second group were more likely to report feelings of helplessness as parents, and in the majority of cases, were not as active in their roles as mothers.[25] A key factor in being able to positively manage “the challenge of motherhood was the extent to which it had been possible for them to reflect on, appraise and resolve psychosocial risk experiences in their lives.”[25, p. 106] As such, Dodsworth recommends interventions that allow women to work through these challenges to build resilience and self-efficacy, while also addressing structural factors that impact their wellbeing and that of their children.[25]

### ***Community Empowerment Approaches***

#### *Existing Frameworks*

In a systematic review of programs utilizing community empowerment approaches to address HIV among sex workers, Kerrigan, et al., define community empowerment approaches as those which are community-led, recognize sex work as legitimate work, do not aim to “rehabilitate” sex workers, and “are committed to ensuring the health and human rights of these individuals as workers and as human beings.”[26, p. 173] One of the first, and most well known, programs to take a community-based approach to promoting the health and human rights of sex workers in the developing world is the Sonagachi Project in India. Sonagachi began in the early 1990’s as an HIV prevention project and grew to focus on peer education, sex worker empowerment and skills building, combating stigma in their communities and advocacy for sex workers’ rights.[27] Though very successful in reducing HIV rates, program impact has far surpassed initial intent and has led to educational, professional, social and political advancement for sex workers in India.[27]

Another successful project that seeks to build upon the Sonagachi model to address broader structural issues which impact sex worker health and safety, such as violence, is Ashodaya Samithi, which is now carried out through the Avahan India AIDS Initiative.[14, 28] This model more closely follows Laverack's definition of community empowerment "as a 'dynamic continuum' from individual action to collective social and political change," as projects evolve along the continuum through various levels of community mobilization and ownership.[14, 29, p. 182] The success of these programs provides testament to the potential advantages of taking community-based approaches to both behavioral and social change, perhaps especially among marginalized groups who may lack social capital or political will on an individual level, as is often the case with sex workers in criminalized settings.[14, 30]

#### *Community Empowerment in the African Context*

Two recent reviews of community empowerment projects targeting female sex workers indicate that very few projects in Sub-Saharan Africa focus on building the capacity of sex worker communities.[14, 26] Both restricted their reviews to programs that offer delivery of sexual and reproductive health services to sex workers, which may have led to the exclusion of program models being utilized outside the context of reproductive health service delivery, however this is also reflective of the fact that the majority of sex work-related research has centered on HIV and STI prevention.[23] The meta-analysis conducted by Kerrigan, et al. measures the effectiveness of community empowerment approaches in impacting sexual health outcomes, demonstrating promising associations with decreased HIV and STIs as well as increased condom use.[26] However as Moore, et al. aptly conclude, programs targeting sex workers in Sub-Saharan Africa are in large part still very much focused on disease control rather than utilizing community empowerment approaches that allow for sex workers themselves to

engage in the development and implementation, or to take ownership of, interventions that allow them to mitigate the many occupational hazards they face.[14]

Moore, et al. cite several structural factors that may be responsible for this stagnation that has been seen in the African context despite engagement with sex workers issues since the 1990s and the relative success of interventions of this type in other locations, such as Sonagachi and Ashodaya in India.[14] Both Moore and Kerrigan discuss structural barriers to successful implementation of such programs in Sub-Saharan Africa, such as national laws that criminalize sex work and the lack of sustainable funding sources.[14, 26] Despite acknowledgement of a push in recent years toward human rights-based approaches to sex work, both articles also point to a need for changing discourse around sex work so that vulnerabilities sex workers face can be treated as occupational risks of a legitimate occupation rather than continuing to view sex work as a societal problem afflicting women who have made “poor moral choices.”[14, 25, 26, p. 182] Moore recommends shifting toward greater control of sex worker projects by communities and using “transformative communication.”[14] Campbell and Cornish describe transformative communication as a process by which “marginalized groups develop critical understandings of the political and economic roots of their vulnerability to ill-health, and the confidence and strategies for tackling them,” to support social and political change.[30, p. 848] This recommendation draws upon the successes of Sonagachi’s work in utilizing this approach, which they further conceptualize as “the pathways to the social changes needed to empower poor people to take greater control over their health and well-being, and to successfully demand access to the political and economic power that would enable them to improve their lives.”[30, p. 848]

### ***Stigma***

Numerous studies provide evidence of the pervasive experiences with stigma among sex workers across various settings. Stigma has often been reported as a barrier to accessing health and social services, but as Duff suggests, it may also influence sex workers' ability to parent.[23]

### *Stigma and Access to Health and Social Services*

WHO guidelines state that “Health services should be made available, accessible and acceptable to sex workers based on the principles of avoidance of stigma, non-discrimination and the right to health.”[31, p. 8] In spite of this, evidence of stigmatization of sex workers in healthcare settings is common.[17, 22] A qualitative study conducted in four African countries found that in addition to barriers to care such as long wait times, limited transportation, high costs, and medication stock outs, sex workers also identified discrimination and “abusive,” “hostile” providers as challenges to receiving health services.[17] Participants in this study describe providers “withholding treatment, referring sex workers unnecessarily, or explicitly blaming sex workers for their illnesses.”[17, p. 5] Issues of confidentiality or violations of privacy and fear of disclosing involvement in sex work were also common.[17] Participants reported unmet need for certain services (i.e. pap smears, condoms) or being turned away due to their status as sex workers. Of particular import was the finding that being refused services was seemingly common in cases when sex workers required treatment for injuries sustained while working including through abuse or rape, when particularly susceptible to mental trauma and risk of HIV infection. [17]

A Canadian study on stigma as a barrier to health services found that over half of street-based sex workers experienced sex work-related stigma, while just under half reported having experienced barriers to accessing healthcare in the past six months.[22] This study also found occupational stigma to be associated with experiencing increased barriers to care.[22] Kurtz also

found stigma to be among commonly reported barriers to both health and social services among sex workers in the United States.[24] Anticipated stigma and a subsequent reluctance to disclose employment as a sex worker or other stigmatized behaviors such as drug use may also influence the quality of care that sex workers receive, as providers are not able to properly assess risks associated with behaviors that have potential health consequences.[24]

Duff, et al. looked specifically at barriers to health and social services for sex workers who were pregnant and/or parenting. One-third of the sex workers in this study reported one or more barriers to health or social services with the most common barriers being lack of financial or social support, and fears of partner violence, apprehension of children by protective services, or other punitive action regarding their children, and fear of stigma.[23] Conclusions drawn from this study suggest that the many barriers sex workers face during pregnancy and parenting require interventions that increase access to “enabling environments that support them as pregnant women/parents.”[23, p. 1051]

### ***Patient Self-Advocacy***

#### *Teaching Self-Advocacy*

Based on reports of negative experiences in accessing health services, it may be useful to incorporate tools for overcoming these barriers in the curriculum. One possible solution would be to promote self-advocacy among sex workers as patients. An advocate is often defined as a supporter or ally – in healthcare, a person who empowers patients to advocate for themselves.[32] Naumann and Vessey argue that personal, societal, and institutional factors influence one’s ability to self-advocate.[32] Key personal factors include knowledge, cognitive abilities and motivation.[32] Knowledge of the healthcare system or one’s body enable people to act as better self-advocates.[32] Similarly, a lack of previous experience or feelings of

discomfort in asking questions of providers may limit one's ability and should be addressed through education, positive reinforcement and through the provision of a space in which patients feel comfortable asking questions.[32] Primary strategies for teaching self-advocacy include education through the provision of age and educationally appropriate materials and building communication skills through practicing negotiation and assertiveness.[32]

### Conclusion

This literature review seeks to guide further curriculum improvement by providing a foundation in the key concepts guiding its development. It also aims to provide justification for recommended changes based on proven models of education and empowerment interventions. Additional information on coping with occupational stresses of sex workers who are mothers, stigma as a barrier to health and social services, and how patient self-advocacy might be used as a tool to mitigate these barriers were included to inform modifications aimed to strengthen existing curriculum materials based on needs identified through preliminary evaluation findings.

## **CHAPTER 3: METHODS**

### ***Program Evaluation***

From June to August 2015, I conducted a program assessment at SWEAT headquarters in Cape Town, South Africa to gauge the effectiveness of existing programs in their ability to meet the evolving needs of service users. Based on needs identified by SWEAT, the primary aim of this assessment was to appraise the progress and acceptability of the recently implemented Mothers of the Future program. To meet the objectives of this evaluation, curriculum sessions



were piloted and assessment using evaluator observation, focus group discussions and pre- and post-test surveys.

### Curriculum Evaluation

Seven of nine sessions of the *Mothers for the Future* curriculum were pilot tested over the course of a three-week workshop. Save for activities that were led by expert facilitators or peer educators, I served as the primary facilitator for each session. Sessions were delivered at SWEAT offices during two-hour blocks three days per week, with approximately twenty women participating in each session. Methods utilized in the assessment consisted of facilitator/evaluator observation (field notes), pre- and post-test surveys, and focus group discussions (FGDs).

### *Population and Sample:*

Participants were purposively selected into the workshop based on involvement in the Mothers for the Future support group. The group included women from two cohorts of the Mothers for the Future program, the “core group” of mothers who had participated in the program during its initial 2014 pilot phase (Cohort 1), as well as the new group of mothers who had not yet had exposure to the program (Cohort 2). Of participants completing the program (defined as attendance at eight of ten workshop meetings), five were from Cohort 1 and thirteen were from Cohort 2. Peer educators also attended workshop sessions and were asked to provide feedback for sessions for which they were present. The majority of participants were street-based sex workers with ages ranging from approximately 25 to 57 years of age and included those who were currently parenting infants to those with adult children, as well as grandmothers.

*Procedures and Instruments:*

*Field Notes*

When available, another member of the EGHI team functioned as note-taker and recorded detailed observations on participant questions, timing of activities, and challenges arising during delivery. An external note-taker was utilized during approximately 30% of sessions. During the remainder of the sessions, I, as the facilitator, recorded personal field observations at the close of the session. Following sessions when the Program Coordinator Ms. Dudu Dlamini was present, she and I would debrief the events of the day so that her feedback on the program could be incorporated into evaluator/personal field notes.

*Pre- and Post-test Surveys*

Along with Ms. Nelson, I developed questionnaires based on curriculum content and included a mixture of multiple choice, true-false, and Likert-scale question items aimed at measuring understanding of key concepts, knowledge gain, and self-efficacy. The final questionnaire included a series of short response questions in order to gain more detailed information on participants' opinions of the program, suggestions for improvement, and to allow participants to share additional thoughts that may not have been captured by the fixed-response questionnaire items. Surveys were conducted on a weekly basis prior to and following the delivery of that week's workshop sessions. Including peer educators and workshop participants who had more than two absences, survey data was collected (in part) for seven additional participants. Participants were assigned unique identification numbers to both ensure anonymity of their responses and to link participant data across administration of multiple pre- and post-tests.

### Focus Group Discussions

Two focus group discussions were conducted with program participants in order to gather information on participant insights on the program including perceived satisfaction, strengths and weaknesses, and gaps in content with the intention to inform future recommendations for the program. Focus groups were chosen for their ability to generate discussion and to highlight common experiences and differences in opinion among group members. The first focus group discussion was conducted prior to piloting the new curriculum materials (n=10), with the second taking place at the close of the three-week curriculum workshop (n=9).

Focus group participants were drawn directly from the Mothers for the Future support group. The first focus group discussion consisted of ten members of the “core group,” or those who had participated in the 2014 pilot phase (Cohort 1). These participants were purposively selected by the Mother for the Future Program Coordinator, Ms. Dudu Dlamini. Participants for the second focus group discussion were selected from among those participating in the curriculum workshop. Women from both Cohorts 1 and 2 were included to elicit a range of experiences. Program participants who had missed no more than two workshop sessions volunteered to participate in this discussion. Volunteers were recruited during the final workshop session. Volunteers who were absent the morning of the focus group discussion were replaced through a second round of recruitment from among workshop participants present on SWEAT premises for that morning’s Creative Space. One participant who was asked to participate refused. One other was excluded after a very late arrival, though two participants arriving after the start of the discussion were allowed to participate. In total, nine mothers participated in the final focus group discussion. One member of the group was pulled out by SWEAT staff during

the session due to another obligation, and was unable to complete the second half of the discussion.

I moderated both focus group discussions using a semi-structured discussion guide. Focus groups ran just over one hour each. Recordings, which I later transcribed, were produced using an audio recording device. Note takers (Ms. Alicia Weigel on FGD 1 and Mr. Michael Vaughn on FGD 2) sat in to capture additional information to supplement audio recordings. Focus groups were conducted primarily in English, however portions of the discussion took place in Xhosa and were translated in real time with the aid of Ms. Dudu Dlamini.

#### *In-depth Key Informant Interviews*

Semi-structured, in-depth interviews were completed with SWEAT key informants to explore participant experiences in accessing and utilizing health care services in Cape Town. Open-ended questions were used to gather information on perceptions of service users' satisfaction with services, decision-making on when and where to access services, experiences with stigma and discrimination, and recommendations to improve access to services.

Key informants were selected purposively from SWEAT staff. A total of four one-on-one interviews were completed. Key informants were identified based on their involvement in specific SWEAT programs that allowed them to work closely with service users and community stakeholders, such as health facilities and the Department of Health. Interviewees included, 1 transgender female sex worker, 1 cisgender female sex worker, and SWEAT staff that were not sex workers (n=2).

Interviews were conducted in English using semi-structured interview guides that were piloted and adjusted iteratively to ensure that key information was elicited from each participant.

Two participants were interviewed using a modified guide that included questions aimed to explore both their personal experiences as former service users and as key informants. All interviews were audio recorded and transcribed with participant consent, by a student assistant and myself.

#### *Data Analysis:*

Field notes were summarized by curriculum session and analyzed for content relating to deductive themes previously identified in the 2014 community needs assessment. Field note data demonstrated how participants interacted with the existing content areas in the study setting. These data were used to assess levels of relevance and familiarity of content amongst participants, and to identify procedural changes to be made to the curriculum. Data from field notes were also matched to inductive themes identified through thematic analysis of focus group, interview, and survey data to provide additional context and supporting evidence for these findings.

Focus group and key informant interview transcripts and open-ended questionnaire responses (in a PDF format) were entered into MaxQDA for qualitative data analysis. Deductive codes drawn from curriculum content and interview and focus group discussion guides were applied to text data. Additionally, through careful review of these data sources, both thematic and “applied” inductive codes were developed. Concepts recurring across data sources were identified and used to develop thematic codes. Thematic codes were then further examined and categorized based on similarity to develop overarching *key themes*, including *support, respect, learning and education, self-esteem, and empowerment/self-efficacy*. “Applied” codes were developed to contextualize how content areas or key themes were discussed among participants

and to denote implications for application to the curriculum. For example, “applied” codes such as *content gap*, *clarification needed*, and *organization* were used to identify the type of change recommended to enhance curriculum materials relating to specific content areas.

Each content area was closely examined, drawing first from field notes to provide context and details observed during workshop implementation. Content-related codes were then analyzed and integrated with field observations to describe the participant and facilitator experiences of each curriculum session. Participant and key informant perspectives sourced from survey responses, focus group discussions, and in-depth interviews were matched to facilitator observations and “applied” codes to then formulate recommendations for future curriculum implementation.

### Ethical Considerations

The Emory Institutional Review Board (IRB) designated this program evaluation to be non-research, and as such official IRB approval was not sought. However, throughout the design, implementation, and data management and analysis stages of the evaluation, ethical considerations were followed according to best practices. All participants engaged in evaluation activities voluntarily and provided informed consent prior to data collection. Written consent was provided prior to data collection at initiation of the workshop. Participants were given copies of consent forms to retain at this time. Additional verbal consent was obtained for participants at the start of focus group discussions, as a reminder of their voluntary participation in all aspects of the program assessment and to confirm consent to be audio recorded. All interview and focus group transcripts were de-identified to limit the possibility of linking participant identities to the information they provided. During survey data collection, participants were given unique IDs

(list maintained separately) so that their names were not linked to their responses. Data was stored on password-protected devices.

### Limitations and Delimitations

Due to time and human resource constraints, there were several limitations to this program assessment. First, the curriculum was not delivered on the intended bi-monthly schedule, and instead was condensed into a three-week workshop. This may have contributed to participant fatigue that may have influenced participant engagement in some sessions. Again, due to limited time, we were unable to pilot the final session of the curriculum and as such no data was collected for the acceptability or improvement of this session. The first curriculum session was piloted among mothers from Cohort 2 only. Because of this variation in population and methodology, assessment data from this session was excluded from this analysis. Under ideal circumstances, each session would have had a designated facilitator from SWEAT staff so that they could familiarize themselves with the preparation and delivery of the curriculum materials, in addition to an external observer to record detailed notes on the timing of activities, challenges and topics generating the most interest. However, because members of the Mothers for the Future team had to complete their regularly scheduled responsibilities in addition to attending the workshop, this was not possible. As a solution to these constraints, I functioned as the primary facilitator, interviewer, focus group moderator, and survey administrator. My dual roles in workshop facilitation and data collection may have influenced participants to respond to questions more favorably. My position as an outsider to the community may have further influenced participants' behaviors throughout the workshop or responses elicited through data collection.

Because the Mothers for the Future team thought it would be beneficial for mothers from both the “core group” and Cohort 2 to participate in the assessment, the group size was also larger than had been anticipated when the sessions were developed. This may have, at times, impacted the ability of all participants to fully engage during all sessions and therefore effectiveness of the activities. Additionally, the larger group may have created unanticipated challenges to completing certain activities that may not have occurred under ideal circumstances.

## **CHAPTER 4: RESULTS**

Program participants provided feedback on the curriculum across various data sources (focus group discussions, open-ended survey responses, and as described through facilitator field notes). Findings are presented below in two sections that aim to 1) describe the overarching experiences of mothers participating in the *Mothers for the Future* program, and 2) evaluate curriculum content areas and processes to generate recommendations for program improvement.

### ***I. The Mothers for the Future Workshop Experience***

In addition to statements demonstrating the general acceptability of the program and satisfaction with the workshop and curriculum sessions, several themes speaking to the overarching needs, values, and beliefs of those participating in the Mothers for the Future group also emerged. These themes describe what the space created by the *Mothers for the Future* workshop meant to participants, in what ways they benefited from participation, what they planned to do with the tools they had gained, as well as suggestions for what a program such as Mothers for the Future should aim to accomplish.



### *General Feedback and Acceptability*

Program participants provided overwhelmingly positive feedback about the *Mothers for the Future* workshop and curriculum materials. Many participants were surprised at how much they felt they had learned, despite having already raised children of their own. One survey response read:

*“Yes, I’m a mother of four but I was amazed at how much I still learned, even though I thought I knew everything about parenting.”* (Participant 1, survey response)

Many reported that the sessions were informative, interesting, and engaging throughout the post-workshop focus group discussion and on short answer survey responses. One participant praised it as a “great learning experience” overall during this final focus group.

Generally speaking, participants seemed to find the pace as well as balance between facilitator-led discussion, group activities, and group discussion to be good, as indicated through focus group questions, survey responses, and brief check-ins, which were administered following sessions. Some participants did, however, report through survey responses that more small group activities, and more “practical” or hands-on activities could have been beneficial. Participants seemed to value some degree of repetition of the material, explaining during both focus group discussions that this helped to further understanding and retention of the topics. Group members recognized that some participants took longer to understand certain topics and during the final focus group discussion reported being content to engage in debate that allowed those participants to gain clarity.

### *Mothers for the Future “Space”*

Taking this last point a step further, the majority of participants found the “space” created by the workshop group to be a safe space in which they felt comfortable opening up and sharing without fear of judgment from their peers. This was discussed at several points throughout the final focus group discussion, as well as mentioned in many of the survey responses. Through discussions of this space, it became clear that the group took a certain level of ownership of this space, often stressing their commitment to participation and their expectations for their peers entering the space to demonstrate a similar level of commitment and engagement during workshop sessions. Women developed a great sense of respect for the space and it was made clear during focus groups and on numerous participant surveys that the support of the group and the opportunity to build relationships with other groups members were highly valued. These values will be further discussed below among the key themes that emerged during thematic analysis of focus group, survey, and field note data.

*“So at least I’m free in the space.” (Participant 4, FGD2)*

*“We are together. We learn a lot, no people judging other one when we share out stories about the pain of abortion.” [sic] (Participant 24, survey response)*

### Key Themes

#### *Support*

Mothers discussed various types of support provided through the Mothers for the Future program. Many highlighted the opportunity that the space provided to get to know their colleagues on a more personal level. The theme of developing a bond with the fellow mothers was recurrent in both the final focus group discussion and survey responses. Evaluator field notes also corroborated a noticeable change in the group dynamic over the course of the three-week workshop. Others liked that during the workshop the group was “working together.”

*“In the space, what I like, I like uh, bond with the mothers... Yeah, mothers must bond, and that they know each other a very long time, but they start to know each other in the space, and then, and then we will have a lot of respect for each other.”*

(Participant 4, FGD2)

Many expressed a willingness or desire to share with the other mothers, and to an extent those in the larger SWEAT community. Sharing was discussed both in terms of tangible things such as food or baby goods, as well as opinions, ideas, and information. The theme of helping others was recurrent, from the first focus group in which the vision for the Mothers for the Future program was discussed to the closing focus group, as well as in individual responses from the questionnaires. At the time, some of the mothers were working on a project to make blankets for babies in need. Some tied their desire for gaining more skills through the program to their desire to be able to help even more by learning to sew, crochet, and even become doulas and home-based caregivers. During the initial focus group discussion, the coordinator of the program also reiterated her desire that this “core” group of mothers who have received the curriculum will be

able to go on to support others in their communities through peer education and home support to ensure their children are going to school, visiting the clinics as needed, and that they are safe.

Many seemed eager to share the information they had gained during the workshop with those at SWEAT and in their communities. During the final focus group discussion, one mother even shared that she had in fact helped another woman in her community in thinking about her pregnancy options after our discussion of the topic in *Session 3: Options Counseling* of the curriculum.

*“I learn that I can help other mothers and my peer with the information that I have”*

(Participant 18, survey response)

*“I learn to share with my colleagues what I have, and also in the communities...I share what I have when I have saved it”* (Participant 17, FGD1)

*“Just help me, helped me to be a better mother, And I’m not gonna be a mother ‘cause I’m 50 years old already, but at least I can um share my- share the information with other young women.”* (Participant 3, FGD2)

### *Respect*

Respect was a prominent theme across the data. The theme of respect came up frequently in the contexts of having respect for the space (within the workshop and group sessions) and for one another. Respect for the space was demonstrated repeatedly through comments toward group members who disrespected the space by not taking it seriously. This behavior often took the form

of coming to the sessions under the influence of substances, sleeping during sessions, or other instances of not abiding to the group's established ground rules for conduct. While the majority of the group did take the sessions seriously and were fully engaged, there were a select few whose behavior was at times disruptive. The group readily expressed their frustrations to the facilitator during session meetings and again on workshop feedback forms and in the focus group discussion at the close of the program. Letting others have the floor during group discussions, listening attentively, and allowing them to express their opinions free of judgment were all discussed as signs of respect for one another. This feedback spoke to a desire for members of the group and for all mothers who are sex workers to demonstrate self-respect and respect for their peers.

*"We all respected the space, and we respected each other's opinions"*

(Participant 3, FGD2)

*"I will only accept mothers who is 100% willing. I would only accept mothers who have respect and integrity. I would only accept those who participate and is willing to go the extra mile together."* (Participant 12, survey response)

Respect was also mentioned frequently in short answer questionnaire responses regarding what mothers most wanted for their children. Many reported wanting to teach their children respect for others. Mothers reported:

*“I want them to be successful no matter what they do as long as they do it with patience, respect and passion.”* (Participant 12, survey response)

*“I want my children to grow with respect and the knowledge that I got from my peers.”*  
(Participant 18, survey response)

### *Learning and Education*

Focus group discussions and survey responses demonstrated not only how much the participants felt they had learned through participation in the program, but also how much they valued the opportunity to learn new information and skills. Many mentioned wanting to have continued training and the opportunity to participate in future workshops.

Skills and training were repeatedly discussed in terms of what the mothers would like to get out of the *Mothers for the Future* program and from SWEAT programming in general. This was discussed in the contexts of wanting to know more solely for personal growth, to be able to parent better, to teach their children and peers, and to help those in their communities; as well as to be able to supplement their income. Many were very excited about the prospect of an upcoming doula training that was to be offered to members of the group in the fall of 2015. Others had suggestions for how the group could continue after the scheduled programming by facilitating sessions on different topics themselves. With access to more information and materials in their own languages, some expressed interest in extending these sessions to others at SWEAT or in their respective communities.

Similarly, program participants discussed education frequently. Most often, education was brought up in the context of their children. When asked what each wanted most for their

children in the future, mothers almost unanimously stated “education.” Many discussions during focus groups focused around ensuring that they were able to provide for their children’s school fees and uniform costs. The mothers discussed wanting to be able to support the children of their colleagues with a special education fund that could provide support to mothers who were sick or pregnant and could not “go to the road,” or to support the families of those who had died. The unique challenge of accessing educational resources for children with special needs also came up. Participants built on this discussion, brainstorming how SWEAT and the Mothers for the Future might be able to assist families struggling with these issues.

### *Self-esteem*

Attributes relating to self-esteem such as pride, confidence, and dignity were discussed both in terms of goals for the mothers themselves and their children, as well as in terms of benefits of having participated in the Mothers for the Future program. Mothers from the “core group” discussed having learned to take pride in themselves as women and as mothers for learning from their mistakes and doing the best that they could to provide for their children.

During a focus group discussion, the Program Coordinator, a mother herself, powerfully proclaimed her goal for the group in saying:

*So when you’re saying something, you’re saying with proud and confident, and saying as mother. I’m standing here for millions of womens, and I’m standing here because I want to see our children, our future for our children, and ourselves as mothers, to be respected. (Participant 15, FGD1)*

Participants reported that their participation in the workshop helped them to speak more openly in group settings. Facilitator field observations also noted changes among some of the quieter group members. Several others agreed when one such participant stated during the final focus group discussion:

*“For some of us are shy, so from that we learn how to talk.” (Participant 11, FGD2)*

### *Empowerment/Self-Efficacy*

In their own words, women reported feeling empowered through information and to be better parents. Many wrote in survey responses that they had learned to be better, stronger, or more responsible mothers indicating possible changes in their perceived parenting self-efficacy. This was reinforced during the final focus group discussion, when several participants stated that they had learned to be better parents.

Survey responses and focus groups alike showed that some believed they had learned to be more effective communicators and others reported gaining confidence in their ability to help others. Another replied that she felt the curriculum had empowered them to speak up and to ask questions in the face of health workers not providing them with enough information regarding their health or the medications and procedures they received.

*“It’s empowered us...To ask questions, not to just keep quiet and go home”.*

(Participant 3, FGD2)



*“It has empower me with more information about being a good mother to your children and the community” (Participant 6, survey response)*

Self-efficacy was also an attribute that mothers wanted for their children, with some stating in their open-ended survey responses that they wanted them to grow up to be independent and successful. One mother’s response linked this goal of independence to the ability to provide an education for her child. When asked what mothers wanted most for their children in the future, responses included:

*“To grow up right and get education so that he can be something in life and be independent, not rely on someone.” (Participant 6, survey response)*

*“I want to see their future bright, learn how to do things in their own, not depend in some people because one day I gonna leave them by died” [sic] (Participant 24, survey response)*

## **II. Curriculum Content Areas & Recommendations for Implementation**

In addition to these overarching themes identified through focus groups and survey responses, which provide insight into the needs, values, and opinions of the mothers utilizing SWEAT’s services, several key content areas are discussed within the *Mothers for the Future* curriculum. Content areas are based on themes previously identified during the 2014 community needs assessment. Throughout the piloting and evaluation of the curriculum, feedback was generated on these content areas through focus group discussions, facilitator observation, and

posttest surveys. Though many of these themes were discussed throughout the three-week workshop as well as during focus groups, findings relating to specific content areas are presented below within the context of their respective curriculum sessions. Corresponding challenges to implementation and recommendations for improvement identified during the assessment process are described by session as well. Sessions 2 through 8 will be discussed in detail, as due to logistical factors during the pilot period, program participants contributed to the evaluation of these sessions only.

***Session 2: Planning Pregnancy & Protection***

This session focuses on family planning and protection from HIV and STIs. Sub-topics included unintended pregnancy, birth control, condom use, sexually transmitted infections (STIs), and HIV/AIDS.

Session 2 Activities	
A. Choosing to Parent.....	10 minutes
B. Contraception.....	25 minutes
C. STDs & HIV.....	35 minutes
D. Protected Sex.....	25 minutes
E. Overcoming Barriers to Safe Sex.....	50 minutes
F. Closing.....	5 minutes

*Planning Pregnancy and Birth Control*

Field notes show that when prompted, participants readily offered several examples of birth control methods that could be used to prevent pregnancy with varying degrees of familiarity. A general, “birth control” was offered, in addition to specific methods such as birth control pills, injections, and condoms. Breastfeeding was also mentioned, in addition to

sterilization and “the loop,” a local term for an intrauterine device (IUD). In the curriculum, only birth control shots, pills and sterilization are discussed in further detail. However, the topic of family planning generated considerable discussion and questions, suggesting the level of detail and time allotted in the curriculum was not sufficient.

There was some debate about traditional methods and whether those could be considered birth control methods. Women offered opinions on which methods might be best for sex workers, citing concerns over occupational factors such as constantly changing schedules and the potential for sleeping through the scheduled time to take pills, not having pills on hand while working, and the risk of having pills taken away. Field notes suggest that injections were commonly used among participants and their peers.

Many women wanted to discuss misconceptions or share anecdotes regarding certain methods, particularly sterilization and the IUD. Several participants had questions regarding the possibility of method failure, citing stories in which acquaintances had fallen pregnant despite opting for one of these long-acting or permanent methods. During the final focus group, one woman illustrated a possible lack of understanding among her peers about proper use and signs of method failure of injectable birth control. As part of a larger discussion regarding the unclear expectations one woman was left with after being sent home with tablets for a medical abortion, this participant replied that she had similar concerns about birth control. She said:

*“Even the birth control also, all of us we know this, we take the three-months injection, bleed through again, then some of us get pregnant. If they can make something stronger to prevent that you’re not – can’t get pregnant.”* (Participant 13, FGD2)

The response of a fellow group member who recognized that one does not typically menstruate when using injection methods demonstrated a range of understanding regarding what to expect when using this particular method. This suggests that there may be value in further instruction on proper use and expectations associated with different methods through the *Mothers for the Future* platform.

One of the older women among the participants cautioned her peers against sterilization, sharing that you may change your mind and want more children later in life. Another shared that she had undergone the procedure and, for her, it was absolutely the right choice. She cited the financial benefits and hardship that having to raise another child on her own would have presented as well as the security that her choice gave her.

When one asked her peer about the procedure and the process for scheduling an appointment, she divulged a particularly illuminating personal story. She revealed that she had wanted to have the procedure done for two years and had been unable to obtain an appointment due to waitlists or being told that she would need to schedule an appointment the next time she visited the clinic. Her story suggested that she was not given clear instruction from health workers and that perhaps she did not know who else to ask, what was to be expected, or with whom to lodge a complaint. During this discussion, there was also a consensus that little information or choice was given when seeking birth control at the clinics. Women expressed frustration that they were not given a range of choices or details on the benefits or side effects of each option. In fact, many said that the health workers would simply choose a method for them.

*Recommendations for implementation:*

*Feedback provided during this portion of the session indicates that there is a genuine interest among participants and a need for more education around birth control options. Participant feedback suggests that women commonly face challenges in accessing this information in the clinics or through other avenues. As such, modification of curriculum materials to allow for more in-depth coverage of family planning methods would benefit the target audience. Additionally, questions and stories raised by participants provided the opportunity to clarify misconceptions around certain methods and to engage in a rich discussion on the personal nature of choices around family planning. Concerns raised by women during both focus groups and as outlined in field notes suggest that an additional focus on how to advocate for oneself as a patient should be integrated into this session or within another module of the curriculum.*

*It is recommended that Session 2 be divided into two separate modules to allow for sufficient attention to be given to each of its very important topics. Session 2A would focus on family planning and birth control, while Session 2B would cover condom use, STIs, and HIV. Condom use may be discussed within each, however the bulk of this topic will be covered in Session 2B, as pertaining to prevention of STIs and HIV.*

<p><i>Session 2 (activities as outlined in original curriculum):</i></p> <ul style="list-style-type: none"> <li>A. Choosing to Parent</li> <li>B. Contraception</li> <li>C. STDs &amp; HIV</li> <li>D. Protected Sex</li> <li>E. Overcoming Barriers to Safe Sex</li> <li>F. Closing</li> </ul>	<p><i>Session 2A: (To renamed Session 2 in revised curriculum)</i></p> <ul style="list-style-type: none"> <li>A. Choosing to Parent</li> <li>B. Contraception</li> <li>C. Talking About Options</li> <li>D. Closing</li> </ul>
	<p><i>Session 2B: (To renamed Session 3 in revised curriculum)</i></p> <ul style="list-style-type: none"> <li>A. Condoms</li> <li>B. STIs &amp; HIV</li> <li>C. Protected Sex</li> <li>D. Overcoming Barriers to Safe Sex</li> <li>E. Closing</li> </ul>

*The language used in the session also requires alteration. Several key examples stand out. First, the explanation of the probability of becoming pregnant without using birth control required further clarification and could be reworded to facilitate better understanding. Secondly, the curriculum states that with sterilization, “you cannot become pregnant ever again.” While cases of unintended pregnancy after sterilization are very rare, statements such as this may be too simplistic. Warnings regarding potential method failure should be explicitly stated.*

*Terminology used in the curriculum materials should match that of the local vernacular. Field notes indicate instances in which the curriculum could be strengthened through modifications to the language used. For example, in the session materials, IUDs are discussed. However, participants referred to this method as the “loop.” While providing the term IUD may be beneficial to increase familiarity with this terminology, the common term “loop” should be utilized as well, so as to facilitate recognition and understanding. Similarly, the section on injectables, or birth control shots, names this method as Depo, however piloting demonstrated that the commonly used names in South Africa are Nur-Isterate and Petogen.*

### *Sexually Transmitted Infections*

According to survey responses, prevention of sexually transmitted infections was among one of the topics that many participants enjoyed most, but also one on which some participants wished more time had been spent. Field notes indicate that most participants had high familiarity with the various symptoms of STIs and recognized the importance of going to the clinic when symptoms were present. Several also discussed the importance of regular screening, even in the absence of symptoms, as well as risks associated with STIs for babies during pregnancy and childbirth. Questions were raised by participants desiring further clarification on infections that

may be sexually transmitted, but which can also be acquired through non-sexual activity (i.e. urinary tract infections, pubic lice, and herpes), the use of home remedies for treatment of gynecologic infections, and on options for post-exposure prophylaxis for HIV.

### *HIV/AIDS*

HIV was among the topics most often reported both among topics most enjoyed and topics on which more information was desired on survey responses. Many participants were most interested in learning more about the Prevention of Mother to Child Transmission (PMTCT) as well as HIV and tuberculosis (TB) co-infection. While these specific aspects of HIV are better addressed during later sessions, questions were raised during this introduction to the topic as well. As indicated in facilitator field notes, many questions centered on PMTCT, ARV use and adherence, as well as reinfection with HIV, the latter of which was a novel concept for group members. Discussion also included post-exposure prophylaxis for HIV (PEP). Activities during this section were well received and engaging, however field notes also suggest that among this group there was a high level of baseline knowledge regarding HIV facts included in curriculum materials.

### *Condoms*

According to field notes, condom use among group members was assumed to be very high. During activities, many women were adamant about not entering into transactions with clients who refused to wear condoms and offered thoughtful solutions to overcoming barriers to condom use. While more vocal participants seemed confident in their ability to correctly use male condoms, the level of knowledge regarding all steps involved was difficult to ascertain.

Additionally, group leaders noted less familiarity with female condoms. It may have been necessary to allow more time for thorough condom demonstration activities. Field notes indicate a strong preference among SWEAT staff to use anatomical models during condom demonstrations, when available.

One key informant's response touches upon each of these topics relating to protection as well as the discrimination that sex workers might face when disclosing their occupation in the healthcare facilities. She stated:

*You know, if you're – it's not easy to go to a cen- clinic every time telling them that you know, um my condom – a a condom broke. Like, let's say, let's take for instance – some HIV, or not HIV-positive, negative or positive, actually. If a condom breaks, you must go to the clinic. If you are negative you must get PrEP. If you are positive, you must get some antibiotics. May that person had an STI, so you must get treatment for that. So if it breaks this week and then I go to the clinic and then it breaks again next week, I'll go back to the clinic and then nurses start complaining. (KI 002, female key informant)*

*Recommendations for implementation:*

*As previously mentioned, due to the depth of information and the amount of discussion generated on both topics of family planning and STIs/HIV, it is recommended that STIs and HIV be covered in a distinct session. Following feedback provided in the initial focus group discussion, those participating in the program in 2014 valued time to ask questions and preferred to take the time necessary to understand a topic. This finding provides further*



*justification for the division of these sessions, despite the tradeoff of necessitating an additional session.*

*Group discussion related to distinguishing between STIs and other gynecologic infections provided the opportunity to review symptoms and to reiterate the importance of being checked by a medical provider before attempting to treat any symptoms independently. Similarly, debate around available options for prevention of HIV post-exposure and treatment of HIV or other STIs, demonstrated there was some level of misunderstanding on these topics. To ensure that accurate information is relayed in the future, the inclusion of facilitator talking points on these issues is recommended.*

*Due to the number of questions around PMTCT, ARVs, and PEP, more information on these topics in this session is to be included in curriculum revisions. While the importance of taking HIV medication daily is stressed in the current materials, participants desired more detail on the topic, such as how closely one must follow dosage schedules, missed doses, and interactions of substance use and ARVs. It would be feasible to include some of these details within the existing activities, allowing for some more advanced concepts to be discussed among participants who are already somewhat comfortable with the fundamentals of the topic. Basic background information on these topics should be included for the facilitator's benefit in anticipation of questions from the group. Additionally, PEP and pre-exposure prophylaxis (PrEP) are absent from the curriculum. Given their potential benefits to the population, increasing usage, and the South African Ministry of Health's new plan to provide PEP and PrEP to all eligible sex workers, it is recommended that these methods of prevention are discussed in this session as well.*

*While it is not likely to be feasible in all settings, the use of anatomical models, when available, as opposed to bananas or other substitutes, should be encouraged during condom demonstrations. The value of allowing each participant to practice with both male and female condoms would outweigh additional time that may be required to accommodate for this. As such, each should complete this activity when possible. Restricting group sizes will facilitate execution of activities of this nature that require additional materials or resources.*

***Session 3: Options Counseling***

This session focuses on the various options that women have when facing a pregnancy, including abortion, adoption, foster care, and choosing to parent.

Session 3 Activities	
A. Introduction.....	10 minutes
B. The Choice.....	10 minutes
C. Abortion.....	55 minutes
D. Foster Care.....	15 minutes
E. Adoption.....	10 minutes
F. Stories and Support.....	15 minutes
G. Closing.....	5 minutes

Field notes demonstrated thoughtful responses to questions about factors that might influence someone’s decision to parent, including financial stability, partner and social support, emotional preparedness, health status, and personal beliefs about the available options. As previously mentioned, one participant demonstrated the practical application of discussing these options when she shared that she had counseled an acquaintance who was experiencing an unintended pregnancy.

## *Abortion*

Field notes show that participants were quite open to expressing their beliefs about abortion, as well as their personal experiences. Stories came out organically as the activities progressed. This discussion revealed a wide range of experiences. One woman expressed relief after terminating her pregnancy, another discussed the negative impact of her partner's opposition to her having an abortion, while another's response illustrated her own moral opposition to abortion and the guilt she felt after choosing to end her pregnancy. Unsafe abortion was discussed, though participants unanimously expressed awareness of the risks involved with these methods. Women also talked about challenges to obtaining terminations in the clinics due to restrictions on when the procedure can be performed, the limited number that can be performed per day, and the perception that not all health workers would readily offer termination as an option.

Focus group discussions included additional experiences with unplanned pregnancy and abortion. To one participant in particular, abortion was a very important topic. During the final focus group she expressed frustration with the level of information that the health providers give to women opting to have medical abortions. Other women agreed that they could be better at explaining the process, warning signs, and managing expectations. She also disclosed her somewhat recent experience with abortion, after which she stopped menstruating. She expressed much concern over this and after two years was still grappling to understand why. She found information provided to her to be insufficient and thought she needed to obtain yet another opinion. The following quote illustrates her situation – the lack of understanding both of what is happening to her body and of what is to be expected.

*“Two years. And then after that I did not see my menstruation. Then I go to the doctor, and that doctor say no, it’s normal. So I don’t understand to- what was normal after I do abortion.”* (Participant 24, FGD2)

Her peers shared her unsettled feelings with the doctor’s explanation and offered support in response. This woman’s survey responses echoed the theme of support, indicating her gratitude for mothers being able to share their stories around abortion within the group.

Inability to access abortion services was also a recurring sub-theme. During the final focus group, one woman shared her desire to have an abortion upon discovering an unplanned pregnancy. However, due to delayed identification or confirmation in a clinic, she was unable to pursue this option and instead carried her pregnancy to term and chose to parent her child.

### *Adoption & Foster Care*

Both field notes and focus group discussions illuminated a range of experiences with foster care and adoption. Though field notes suggest that the concept of adoption may have been more straightforward, more women seemed to have personal experience with foster care. The final focus group discussion indicated a need for clearer presentation of the differences between the two. Questions noted in session field notes also suggest a content gap surrounding familial agreements for long-term childcare, whether formal or informal, and how these might differ from being placed in the foster care system.

Multiple participants shared stories of having their children taken away or witnessing others going through this experience. A recurring sub-theme was the idea of “grab and go” situations in which social workers remove children from their mothers, and mothers are often

under informed about their rights and how to navigate the system when this occurs. Mothers shared challenges in trying to obtain custody of their children again and, in some cases, a lack of awareness regarding their visitation rights.

Specific obstacles to maintaining or regaining custody were mentioned, such as occupational stigma and discrimination, substance abuse, and unstable housing. During the session, a woman described a case in which she was asked to sign away her custody rights without fully understanding what it was that she was signing. Another emphasized that having children taken away may be of even greater concern to women experiencing homelessness. While this is a clear case in which the impact of unstable housing may be relevant to discuss, the general suggestion was also made to incorporate more information reflective of homeless individuals' unique needs throughout the curriculum.

### *Choosing to parent*

Because the remainder of the curriculum sections is focused on various aspects of parenting, choosing to parent is discussed only briefly within this section as one possible option for women during pregnancy.

### *Recommendations for implementation:*

*The activities related to abortion outlined in the curriculum materials were engaging and generated rich discussion. The opening activity caused minor confusion, as such it is recommended that modifications be made to the activity and/or to the language used in the instructions. Because it involved shouting out different fears and emotions, there is potential that*

*it could have made some participants uncomfortable. Expectations of termination of pregnancy procedures should be addressed in more detail in the curriculum.*

*Simultaneous presentation of adoption and foster care may help to bring clarity to the distinction between the two. As such it is recommended that activities on these topics are merged in the revised curriculum. Variations of these concepts, such as open adoption and fostering among extended family members should be discussed and clarified as well. Inclusion of a diagram or flipchart activity comparing these differences is also recommended. This section is also one instance where diverse living situations should be taken into account. Specifically, strategies for women and children experiencing homelessness should be discussed.*

*Experiences shared during focus groups and throughout the session point to a need for greater detail on how to exercise rights related to both abortion care and child custody. Resources such as Women's Legal Center are discussed within the session materials, however linkage to further resources and/or tips for navigating social and child protective services would be beneficial. Discussions detailed within this content area further support a need for more tools related to advocating for oneself as a patient. An additional activity aimed to further develop these skills should be incorporated into the session.*

*Additionally, the final activity is time allotted for stories and support. During piloting, stories were shared throughout when relevant topics were introduced. It may be more realistic to work this additional time into each of the activities during future implementation to allow for greater interaction. As such, suggested activity times should be modified.*

#### ***Session 4: Pregnancy***

This session focuses on pregnancy and includes discussions on biological changes that occur during pregnancy, how to stay healthy during pregnancy, substance use, Fetal Alcohol

Syndrome (FAS), prevention of mother to child transmission of HIV (PMTCT), childbirth, and what to expect after delivery.

Session 4 Activities

A. Introduction.....	10 minutes
B. Healthy Mother, Healthy Baby.....	35 minutes
C. Growing Belly and Baby.....	15 minutes
D. Pregnancy Complications.....	20 minutes
E. HIV and Pregnancy.....	20 minutes
F. Delivery and Post-delivery.....	15 minutes
G. Closing.....	5 minutes

Participants were engaged throughout this session and readily shared experiences and advice for others. Activities involving listing signs of pregnancy, what to do to stay healthy during pregnancy, and how to save money to prepare for missed work due to childbirth, allowed women to draw upon personal experience.

*Antenatal care*

Field notes denote some debate around when a woman should first visit a clinic if she has a confirmed or suspected pregnancy. During conversations about the importance of antenatal visits, some women expressed challenges scheduling appointments. These challenges left them feeling, at times, frustrated with the clinics, and might potentially deter some from following through with recommended visits. They discussed time as a barrier at certain clinics, stating that they had to arrive very early in the morning and had substantial wait times before being seen. These findings signify that some of the suggestions offered in the curriculum materials may not always be feasible given the realities of how the clinics operate.

As part of a conversation about interactions with clinic staff, one key informant shed light on women's experiences in going to test for pregnancy and/or discuss their pregnancy options. She suggests that some women may not visit the clinic at the first sign of pregnancy.

*“They go halfway [through pregnancy], then they know they don't need to go a lot...*

*They don't go from when they get the symptoms, mm, the signs. Then they have to accept it.” (KI 004, female key informant)*

### *Substance use*

Substance use was another engaging topic both in the session, as well as during focus group discussions. While participants demonstrated a relatively high level of awareness that drinking and smoking during pregnancy could be harmful to their babies, many still had questions regarding this topic. Questions centered on whether small amounts of alcohol were safe. One participant mentioned having heard that small amounts of wine each day could be beneficial during pregnancy. Facilitators should have clear guidance on how to respond to misinformation such as this, so as to ensure these potentially harmful ideas are not perpetuated.

Field notes show that Fetal Alcohol Syndrome (FAS) also generated a large number of questions. Participants had varying ideas about what effects FAS could have on a child. While the curriculum materials do offer some examples, it may be helpful to include a more concrete description of common symptoms so that facilitators are able to dispel incorrect information.

This section includes an activity in which participants are asked to give advice to Thandi, a fictional character who is used as an example throughout the curriculum, on how to stop drinking. Women offered thoughtful advice, incorporating points discussed earlier in the session.



Additionally, focus group discussions suggest that many participants found exercises in which they had to role-play or act out conversations helpful.

### *Pregnancy Complications*

Field notes indicate confusion amongst many of the participants during the activity outlined in this section. Participants were asked to move from one side of the room to the other depending on whether symptoms described were indicative of a serious complication or within the range of normal pregnancy symptoms. Many participants seemed unsure of when to move or, alternatively, were reluctant to do so. Women generally had a good grasp on symptoms that were safe and those which were not, with the exception of a few outliers. Questions regarding swelling of the legs led to the greatest amount of debate, as some women had themselves experienced swelling during their pregnancies without consequence. Clarifying the distinction between normal swelling and warning signs of potentially dangerous swelling would be helpful. In addition, existing curriculum materials include very limited detail regarding implications of swelling and other warning signs discussed. Explanations of conditions associated with symptoms described would likely improve understanding and may help to instill a sense of urgency in seeking help when such symptoms are observed in the future.

Focus group discussions and key informant interviews also revealed anecdotes of note regarding pregnancy and childbirth. For example, one woman shared a personal experience during which she suspected that she was pregnant, was told by a physician that she was not, and then later found out when she lost her baby that the doctor had been mistaken. This woman alluded to the trust that women often place in their physicians and how this might conflict with one's own intuition. This might be applied to the curriculum by emphasizing that women have

confidence in their ability to judge symptoms they are experiencing and the importance of advocating for oneself.

### *PMTCT*

Field notes and questionnaire responses indicate that participants had a high number of questions regarding pregnancy while HIV-positive and the prevention of mother-to-child-transmission. Women stressed the importance of visiting the clinic before getting pregnant when planning a pregnancy as an HIV-positive woman, so that she can improve her chances of following recommended steps and reducing transmission. During this session, a counselor from SWEAT's partnering clinic, TB/HIV Care Association, joined the group to guide participants through this segment of the session and to answer questions. This proved to be very beneficial, as she was able to share details regarding the appointment process and current recommendations in South Africa, as well as provide additional reading materials on PMTCT for the women to take home. Despite this, survey responses indicate that many participants would have liked to spend more time on this topic. Many questions came up that were specific to PMTCT and breastfeeding, however in the curriculum, this topic is discussed separately within the session on breastfeeding. Facilitators may find it difficult to hold all questions related to breastfeeding until that session. As such it may be beneficial to introduce some content on breastfeeding and PMTCT in Session 4. This would also allow the group to maximize the benefits of having an expert/guest facilitator present and would eliminate the need for scheduling additional facilitators to for both sessions.

### *Delivery and post-delivery*

Only brief activities covering childbirth and what to expect after delivery are included in this session, with a total of fifteen minutes allotted for coverage of these two topics. Currently, materials include sharing strategies that helped women feel at ease when going into labor and a discussion of biological changes to be expected after delivery. Women shared birth stories, strategies that helped them mentally prepare before the births of their children, and the experiences of meeting their children for the first time. Participants expressed a range of experiences, which directed the conversation to premature birth, substance abuse and accusations of child abuse, miscarriages and complicated deliveries, as well as the importance of advocating for one's own health. When one participant said that she would have liked to learn more about labor during the final focus group discussion, participants agreed that labor and delivery were topics they would want to know more about. This sentiment was again corroborated through survey responses. Additionally, through survey responses, multiple participants suggested that topics covered in this session would be important for others to know and one reason they would encourage other women to participate in the program. Field notes also comment on the description of postpartum depression and the "baby blues" in the curriculum, with the suggestion of making a clear distinction between normal "baby blues" and postpartum depression, which can be a serious condition.

During the initial focus group discussion, women recounted the death of a colleague the year prior who was "staying under the bridge" and alone at the time of her delivery. This particular story was relevant on several accounts. It was told within the context of needing to increase outreach to women who were not coming to SWEAT or utilizing the clinics during pregnancy with a view to keeping those women and their babies healthy. It was also used to illustrate the risks that women incur when they continued to work throughout their pregnancies,

which was often the case. Though perhaps uncommon, maternal death is one such outcome for which risk may be magnified for women experiencing homelessness, working late into their pregnancies, or who are not utilizing health services. Given the commonality of these experiences among program participants, this increased risk warrants mentioning in this section.

Finally, this story reinforces the need for additional support for sex workers during pregnancy and during the postnatal period. At the time of the pilot, SWEAT was in the process of organizing a doula training for a select group of women with the hopes to expand their ability to offer training in home-based care to interested service-users, beginning with the mothers group. The coordinator of the program also shared her hope to integrate a mechanism to provide for maternity leave for sex workers into the Mothers for the Future program in the future. Provision of education and strategies for peer support through the curriculum in addition to these efforts would afford SWEAT another opportunity to address these issues in the community.

*Recommendations for implementation:*

*More concrete detail on FAS and potential risks associated with drinking and substance use during pregnancy should be included here, if only as optional information to be shared as needed.*

*Activity instruction for Activity D (Pregnancy Complications), should be clarified so as to avoid challenges during future implementation. Recommending the facilitator begin with an example round would be one simple way to ensure that instructions are understood prior to beginning the game.*

*Due to the volume of questions around antenatal care while HIV-positive and the knowledge level required to respond appropriately, it is strongly recommended that an expert*

*facilitator join the session for the PMTCT portion. Field notes suggest that facilitators should be contacted with advanced notice and followed up with prior to the session date to confirm availability. Focus group discussions denote that allowing for post-session follow-up for additional questions with any guest facilitators may also be beneficial. As such it is recommended that a mechanism for follow-up be implemented.*

*The delivery and post-delivery exercises should be expanded to provide additional detail. A brief introduction to the childbirth process and delivery options are recommended additions to the revised curriculum. It is recommended that the presentation of postpartum depression be modified and that resources for coping with mental health during and after pregnancy be included. Based on anecdotes shared during focus group discussions and key informant interviews, warnings regarding maternal death, explicit discussion of miscarriage and stillbirth, and information in support of facility-based delivery should be included here. Field notes suggest further promotion of delivery in a hospital for HIV-positive women be included. This content should be covered by guest facilitator. Focus groups also demonstrate that participants desired information on how to assist peers through labor and delivery. Reinforcement of advocacy skills or additional tools advocating for one's peers or oneself should be incorporated into this session. Depending on capacity and availability of facilitators, there may be potential to include some elements of formal doula support training within the session. However, due to timing this might be better addressed through the addition of a supplemental session or other workshops at SWEAT.*

### ***Session 5: Children's Health***

This session focuses on childhood immunizations and illnesses, with specific detail presented on diarrhea, dehydration, tuberculosis (TB) and HIV.

Session 5 Activities:

A. Introduction.....	10 minutes
B. Immunizations.....	10 minutes
C. Colds.....	20 minutes
D. Diarrhea and Vomiting.....	30 minutes
E. HIV and TB.....	15 minutes
F. Role Play.....	30 minutes
G. Closing.....	5 minutes

*Immunizations*

Field notes indicate that the majority of participants were familiar with immunizations. However in addition to terminology utilized in the curriculum materials, the terms “injections” and “inoculations” were commonly used to describe them. Focus groups demonstrated that one item that stood out to participants with regard to children’s health was the importance of taking children for their immunizations. During focus groups, women also expressed the interest in raising awareness among their peers about the importance of vaccination. The activity covering measles and vaccines was difficult to operationalize and may not have added very much to overall understanding. Facilitator notes indicate that modifications to the props utilized, number of volunteers used for demonstration, and clarification of language used to explain this process may be helpful. Participants also found discussion of the immunization schedule helpful, though many questions regarding specific vaccinations (polio, chicken pox) were posed, along with possible discrepancies in the recommended guidelines/timeline for vaccination. In the current materials, flip chart and individual cards to be handed out to mothers outlining the immunization schedule describe ages at which immunizations are recommended only. As some women proved to be curious for more detail, it is recommended that the names of immunizations that are typically given at each time point be included as well.

### *Childhood illnesses*

Going over warning signs for serious childhood illness seemed to be a helpful, yet relatively straightforward portion of the session. Familiarity with common childhood illnesses and how to treat them seemed to be high amongst group members. Props and materials intended for demonstrations of how to unblock a child's nose and care for a baby with a fever were not all available, however talking through how to complete these activities seemed to be effective in the absence of demonstration. Many women were familiar with the methods described. During the discussion of how best to care for a child with a fever, one participant suggested using cold water. This suggestion was corrected with recommendations to instead use warm water. Recall of warning signs and treatment seemed to be high during the final focus group discussion.

The activities on dehydration, diarrhea, and vomiting also proved to be useful. The belly test for dehydration described in the session materials was noted to be novel information to the majority of the group, suggesting that its inclusion was beneficial. Many participants had prior knowledge of the "home mixture" that is provided as a remedy for dehydration, though the recipe that they shared differed from that in the curriculum. This discrepancy seemed to be based on the quantity prepared however, and was otherwise equivalent. Mention of this alternative recipe may be useful so as to remain consistent with what women may have learned elsewhere. Additionally, operationalizing this activity with a large group was time consuming and a bit challenging, providing further justification for limiting group size.

Additional barriers to keeping food and water safe were discussed, such as frequent flooding in the townships (informal settlements) and limited food storage options. Participants discussed community efforts to make homes safer as possible solutions to these challenges. Provision of a dedicated forum to brainstorm solutions within the session may be beneficial. This

may also be an appropriate time to include mention of options for those who are experiencing homelessness or housing instability, as requested by one participant during the final focus group discussion.

### *HIV and TB*

This section discusses recognition and treatment of these two common serious childhood illnesses. Survey responses and the final focus group discussion indicate that some participants would have liked more information on HIV, as well as how TB and other illnesses might impact children living with HIV.

Field notes show that participants had thoughtful suggestions to offer in terms of how to ensure that their babies could take their TB medicine if too young to swallow pills, as well as how they, as parents, could remember to administer medication properly throughout the very long period of treatment. While the curriculum does stress the importance of taking the medication every day, it may be helpful to explain some potential risks of defaulting on medication regimens, such as drug-resistance. This may provide additional motivation for adherence. Strategies for the prevention of reinfection with TB were less obvious to the group initially, but participants offered suggestions of routine check ups for their children and encouraging the regular testing of caregivers and children in crèches. The option of utilizing TB prophylaxis (Isoniazid) was raised as well. Provision of additional detail in the curriculum materials may have been helpful in order to allow the facilitator to field anticipated questions on this method of prevention.

This section focuses heavily on TB, and may be further improved by including additional details on how to care for infants/children living with HIV that may not have been covered in



*Session 5: Pregnancy.* For example, neither session includes a discussion of early infant testing and diagnosis. Infant HIV testing is mentioned briefly in one example given in the context of testing after a mother notices her baby is not gaining weight. It seems that this would be a valuable opportunity to also educate mothers on recommendations for infant testing and the importance of initiating treatment early for babies that test positive. Given participant feedback, additional time to discuss extra precautions to keep HIV-positive children healthy may be beneficial as well. Participants posed questions regarding the possibility of reinfection of HIV-positive children with a second strain of HIV through breastfeeding by mothers with HIV superinfection (infection with two or more strains of HIV). Additional information should be included to aid facilitators in responding to this topic in future sessions.

*Note:* Due to time constraints, the final activity, *Health in Action*, was not completed during piloting. This is a role-playing activity that presents different scenarios in which sex workers must advocate for their children's health. Given feedback from focus groups and surveys regarding the utility of role-playing activities and the demonstrated need for more tools in patient self-advocacy, this activity may prove to be quite useful. It also includes a review of several key concepts covered in the session.

*Recommendations for implementation:*

*Language used to define immunizations should be comprehensive to include terminology that might be used by the population, such as "inoculations" and "injections" in addition to "immunization" and "vaccine" in order to maximize comprehension. The activity designed to explain how immunization functions should be modified to improve clarity and increase*

*volunteer interaction. Facilitators should anticipate questions regarding specific vaccines, and as such it is recommended that common immunizations should be mentioned in addition to measles. Flip chart and immunization schedule cards should provide further detail regarding which immunizations are given at each time point. In an effort to arm women with tools necessary to advocate for their children's health, increasing familiarity with names of key illnesses and medications about which they might need to ask their providers could be advantageous.*

*Strategies for keeping children safe and healthy, including preventing dehydration and diarrhea, may be different depending on mothers' living situations. This session provides an appropriate place to include discussion of the distinct strategies that mothers might use based on their unique housing situations and available resources, as was suggested during the final focus group discussion. Activities should be expanded to include tools for women with unstable housing situations or who are experiencing homelessness.*

*In light of participant questions recorded in field notes, additional talking points on TB prophylaxis should be provided for facilitators' use. More detail on the interaction between TB and HIV would be beneficial. It is recommended that basic tips and strategies for taking care of children with HIV or HIV and TB be included in this section as well. Hypothetical scenarios provided in the activities briefly discuss infant testing for HIV, however a more detailed overview of recommendations on this topic should be included.*

*Timing of this session also presented an issue. As noted above, this session ran long, and as such the final activity was not completed. Time allotted for this session should be extended to 2.5 hours (in place of the current 2 hours) to allow for the completion of this final activity.*

## ***Session 6: Breastfeeding***

This session focuses on exclusive breastfeeding, including barriers to and facilitators of breastfeeding, breastfeeding when HIV-positive, and formula feeding.

### Session 6 Activities:

A. Introduction.....	5 minutes
B. Breastfeeding Basics.....	25 minutes
C. Breastfeeding Benefits.....	20 minutes
D. Breastfeeding and HIV.....	20 minutes
E. Breastfeeding Practice.....	40 minutes
F. Breastfeeding Barriers.....	40 minutes
G. Formula Feeding.....	15 minutes
H. Closing.....	15 minutes

Breastfeeding was among the most frequently mentioned topics on survey responses and in focus group discussions. Women highlighted breastfeeding as a topic on which they had learned a great deal. In addition, breastfeeding was frequently listed as a favorite topic among those discussed throughout the workshop.

### *Breastfeeding basics*

This session begins by asking participants to describe what breastfeeding is. Field notes indicated that this seemed redundant, as almost everyone in the group had personal experience and breastfeeding had already come up in several discussions during previous sessions (i.e. *Session 4: Pregnancy* and *Session 5: Children's Health*). The group instead began to discuss exclusive breastfeeding, which had also been touched upon, but not formally introduced, in these previous sessions. As such, reviewing this definition here seemed to be advantageous.

The discussion on colostrum that followed was also valuable. The majority of the participants were familiar with the concept, however many were unfamiliar with the name and

dialogue demonstrated that many held varying, sometimes misinformed, beliefs on the topic. Some participants shared myths they had been told about colostrum, some of which were widely accepted amongst group members. One mother who had recently given birth shared that she was told it acted to cleanse the baby's system and to prepare the baby for being able to digest the breast milk that would follow. Field notes suggested that at the end of the session, others were still unconvinced of the health benefits of colostrum, despite a lengthy discussion presenting supportive arguments.

During the segment on breastfeeding for sick children, group members readily recalled the home rehydration mixture mentioned in the previous lesson. They also recognized that one should discuss any medications with a health worker before administering them to a baby. The curriculum materials stressed that unless otherwise directed by a health provider, breast milk alone should be sufficient for those who are exclusively breastfeeding. However, it should be made clear that mothers should continue breastfeeding and refrain from administering oral rehydration therapy to infants who are exclusively breastfed *unless* recommended by a health provider.

Field notes indicate that in addition to being problematic in terms of instruction and logistics, Activity B (Breastfeeding Basics) was somewhat redundant. Some questions included were direct repetition of information presented in the introduction, rather than building upon what was presented. The activity also instructs the facilitator to hand out orange slices as “prizes” for participation, to be used during a later activity. This proved to be distracting and should be substituted for an alternative “reward.”

Activity C (matching pictures to breastfeeding benefits) generated discussion about the benefits of breastfeeding, which seemed to be both more engaging and beneficial than the

previous activity. However, pictures used in the activity were not all clear representations of the concept or benefit that they represented, making it, at times, challenging for the group as well. An image depicting breastfeeding as a form of birth control demonstrated that this was a novel idea to some members of the group, while others were familiar with breastfeeding's ability to reduce likelihood of pregnancy. Facilitator notes suggest that the language used to describe in this section should more explicitly state possible method failures associated with using breastfeeding for the purpose of delaying pregnancy.

### *Breastfeeding and HIV*

Focus group discussion, survey responses and field notes all indicate that the issue of breastfeeding and HIV was both important to participants and an area on which they felt more time could have been devoted. This section allowed for discussion of questions that had not been covered during the session HIV and pregnancy as well as further clarification and review of issues previously mentioned. One woman suggested that formula feeding was a good way to prevent transmission from mother to baby. The discussion that followed indicated that this was the advice that many women had received in clinics, despite current WHO guidelines that promote exclusive breastfeeding for HIV-positive women.[33] Many women were surprised to learn that HIV-positive mothers could breastfeed with the use of ART and/or infant prophylaxis such as Nevirapine, as was reiterated numerous times in field notes, survey responses and the final focus group discussion.

*“As an HIV-positive mother, I never know that I can breastfeed my child, but here I’ve learnt that I can also breastfeed my child” (Participant 11, FGD 2)*

Common questions pertained to ARV adherence, medication for infants such as Nevirapine, and why weaning should occur at six months postpartum for infants of HIV-positive mothers. Additional questions related to pregnancy such as the importance of HIV testing early in pregnancy and birth options for women who are HIV-positive. Though these latter topics are more relevant to previous sessions and are addressed to some degree in Sessions 4 and 5, facilitators may anticipate further questioning as issues related to PMTCT during breastfeeding are discussed.

### *Breastfeeding practice*

Participants offered some recommendations that differed slightly from those provided in the curriculum materials in terms of the correct method for supporting breasts during breastfeeding. At the same time, the majority agreed on other key components of good breastfeeding practice such as always being seated while feeding, skin-to-skin contact (also discussed by participants as “kangaroo care”), strategies for encouraging breastfeeding infants to latch, positioning babies’ mouths around the entire areola rather than just the nipple, and that sucking sounds during feeding were an indication that the baby needed to be repositioned to reduce air intake. Despite a relatively high level of knowledge on breastfeeding practice, participants seemed to enjoy the latching demonstration using orange slices described in the curriculum materials. Field notes also indicate that participants agreed this could be particularly helpful for new mothers who were unfamiliar with breastfeeding practices. The term “latch,” however did not translate well and required further explanation in for Xhosa-speakers.

Women readily suggested strategies for identifying hunger in infants, but found identification of signs that a baby might not be getting enough milk more challenging. When

asked about ways to increase milk production, a dialogue was initiated. Several participants mentioned a pill that you could get from the clinic, an item that had not been discussed in the curriculum materials, in addition to home remedies including ginger beer and foods containing yeast. The validity and safety of these options will be further researched before including them among possible responses. One mother had heard that drinking Guinness (malt beverage) could increase milk production, while another mentioned hearing that Smirnoff (vodka) could be used. This provided an opportunity to discuss the safety of drinking while breastfeeding. Further information regarding alcohol consumption while breastfeeding would be helpful to include here, as substance use was a common theme across workshop field notes, focus groups discussions, and survey responses.

### *Breastfeeding barriers*

The activity on breastfeeding barriers was a game in which teams of participants had to make recommendations to address challenges associated with breastfeeding, similar to the activity used in *Session 2: Planning & Protection*. Participants did well in identifying strategies to overcome the scenarios described in the activity. Hand expression generated some discussion, particularly in terms of expressing milk into a cup to be used later or for a caretaker to feed their babies while they were at work. This seemed to be a suggestion that participants found useful. Hand expression was specifically highlighted in the final focus group discussion as something that was learned during the workshop.

### *Formula feeding*

This portion of the session was fairly straightforward. Many women had had experience with formula feeding, however the opportunities to emphasize safety precautions when using formula, and to reiterate the benefits of breastfeeding and the ability of HIV-positive women to breastfeed, were valuable points of discussion. This section also aimed to help women feel secure in their choice to formula feed when that was the best available option, while also thinking about creative solutions to make breastfeeding a more feasible option, even as a working mother.

*Recommendations for implementation:*

*As informed by findings from field notes, it is recommended that breastfeeding be formally introduced in an earlier session. As the topic came up organically in Session 5: Pregnancy, a brief introduction should be included among those materials.*

*Redundancies should be streamlined and activities should build upon information presented through introductory materials in order to challenge participants and make the activities more engaging. Modifications of this nature should be made to Activity B (Breastfeeding Basics), in particular. Allowing participants to first attempt to answer questions outlined in the activity on breastfeeding basics before presenting information to the group may be a useful tool to gauge existing knowledge, encourage discussion, and reduce redundancy. This approach should be used, particularly among groups with more advanced knowledge. Introductory/explanatory language should, however be retained in the materials for participants with a lower level of baseline familiarity with the topics. Handing out oranges as rewards for participation during the activity caused distraction rather than helping to facilitate discussion and as such it is*



*recommended that distributing oranges be delayed until needed for the latching demonstration activity.*

*Risk of pregnancy associated with using Lactational Amenorrhea Methods (LAM) for birth control should be clearly articulated alongside presentation of this potential benefit of exclusive breastfeeding. Additionally, it is recommended that a brief discussion on breastfeeding and alcohol consumption be included in this session.*

*The lack of awareness on the safety of breastfeeding for mothers who are HIV-positive and on ART may be reflective of recent changes to national guidelines, challenges to disseminating such information to clinics or through community-based campaigns, difficulties in changing beliefs and attitudes, or a number of other factors. Providing education to mothers' groups, however, could offer a valuable opportunity to share this information more broadly through peer networks. With this opportunity also comes the responsibility to ensure that accurate information is provided. As such, equipping facilitators with additional resources on breastfeeding and PMTCT or utilizing expert facilitators for this session would be essential. Necessary provisions should be made within the curriculum materials. It is also recommended that additional information on Nevirapine be included to allow facilitators to field questions on this prophylactic method and to explain how it differs from ARV therapy.*

**Session 7: Food & Finances**

This session focuses on weaning, healthy foods, budgeting and grants.

Session 7 Activities:

- |                      |            |
|----------------------|------------|
| A. Introduction..... | 10 minutes |
| B. Weaning.....      | 30 minutes |

C. Healthy Food, Healthy Amount.....	40 minutes
D. Budget.....	30 minutes
E. Grants.....	30 minutes
F. Closing.....	10 minutes

*Weaning*

In preparation for discussion of weaning, exclusive breastfeeding was again covered in the introduction to Session 7, as well as in Activity B (Weaning) . Effects of this repetition may have been exacerbated due to the condensed time in which curriculum sessions were delivered. However as described in my field notes that at least one participant expressed what was interpreted as exasperation when a question on the topic was posed to the group again. It may not have been necessary to review the definition, as at that point in the workshop, participants seemed to have a good handle on the concept. Instead, it may have been more enriching to frame the discussion in this session in a new way. The activity that immediately followed asked women to identify healthy foods for their children, which the majority of participants did with ease. Women then applied healthy food choices to different periods of the weaning process. According to field notes, some questions arose regarding weaning practices when breastfeeding and HIV-positive. This would be an appropriate place to reinforce recommendations for PMTCT and breastfeeding.

*Healthy foods and meal planning*

This section outlines how frequently children should be fed and the benefits of giving a variety of foods, including proteins and fruits and vegetables. It includes reminders to continue breastfeeding until the child is two years old. However, field notes from the session on breastfeeding suggest that the majority of women are unable to continue breastfeeding for that

long and, as such, perhaps this could be phrased in a manner that is more inclusive of participants' diverse choices. Field notes indicate that the group enjoyed the meal planning activity, though finding a variety of foods that could be combined across meals may have been a challenge. Despite familiarity with healthy food options, some mothers raised concerns about being able to afford healthy food options. The group shared thoughtful ideas on how to reduce spending on healthy foods, including going to local churches or organizations that give out food parcels, growing vegetables or other edibles in small home or community gardens, going to wholesalers and buying larger amounts of fruits and vegetables that could perhaps be split among multiple families.

### *Budgeting*

Budgeting was among the most often mentioned topics in survey responses in terms of what participants learned and enjoyed during the workshop. Facilitator observations also made note of a high level of interest among the group members, perhaps suggesting more time could have been spent on the topic.

As a group, participants brainstormed items that might contribute to monthly costs. At the same time, women were able to estimate their own expenses and expenditures on individual worksheets. Field notes indicate that women found this exercise helpful, in that it allowed them to see what they were spending on "fun" or unnecessary items, and where they could cut back, if needed. There was some debate around whether to include items such as alcohol or substances on one's budget. Many participants agreed it was crucial to include such expenses so that they could be aware of how much of their income was being allocated to these items. One mother thought a monthly budget was unrealistic for many sex workers. She shared her personal strategy

of budgeting on a daily basis, noting how she prioritized and decided what portion of her daily income should go toward electricity, food, nappies, and other essentials. Another concern that many participants shared was the ability to save money without a safe place to keep it, and specifically, without access to a bank account. Participants requested resources for help opening bank accounts, and it was suggested that having someone to guide them through this process would be beneficial. It is possible that this could be incorporated into the curriculum itself, but may also be posed as a recommendation to be implemented outside of the curriculum.

The idea for the creation of a shared fund for the mothers was discussed during this session as well as in the pre-workshop focus group discussion. Women expressed the desire for some mechanism to support them when pregnant (i.e. maternity leave) or in the event of an emergency.

### *Grants*

Grants were an important topic of conversation across focus group discussions and within field notes gathered during this session. Costs associated with childcare, the need for additional support to cover these costs, challenges to obtaining grants, and limitations of available grants were common subthemes in focus group discussions.

Field notes indicate some discrepancies in eligibility criteria and details for how to obtain Child Support Grants as outlined in the curriculum materials. Participants indicated that children are eligible to receive grants up to age 18, or 21 if still in school, as opposed to age 7 as listed in the materials. Further research will be completed to corroborate these details in order to ensure accurate information is presented. In regard to the process, women stated that, except for in extenuating circumstances, one could apply for a grant directly through the South Africa Social

Security Agency (SASSA), rather than first visiting the Department Social Development (DSD) as is recommended in the curriculum.

Other questions regarding the documentation required to apply for grants led to interesting conversation and also pointed to a need for additional information. Some women felt the information provided was inadequate because the process outlined assumed that the women themselves had birth certificates, which several did not. Women expressed frustration at not knowing how to obtain proper identification or birth certificates for their children without this essential document. Cost was a concern for some as well. While the curriculum materials state that new documents (not replacements) should be given free of charge, some argued that in practice, this might not always be the case. Another woman shared that SWEAT could offer some assistance to those seeking to obtain documentation. Additional questions regarding how to obtain a passport were also raised. However this issue may be better addressed via other avenues, as it may not directly pertain to the areas of health and/or parenting.

Another interesting point of conversation was surrounding the requirement of a police affidavit to prove unemployment status or proof of income under 800 ZAR. More than the potential anxiety at having to visit the police station to obtain this, women expressed feeling conflicted in pledging their unemployment status, while at the same time fighting for the recognition of sex work as a legitimate occupation. Others were firm in their belief that claiming unemployment was acceptable until sex work was decriminalized and recognized under the law. Women also shared that they would not disclose their sex worker status in these situations, for fear of being laughed at.

Though not directly related to obtaining financial support, the discussion then shifted to disclosure of involvement in sex work in clinical settings. Women almost unanimously agreed

that they would not disclose this information to nurses at the clinics for fear that they would tell their colleagues. They also shared general experiences of being shamed by nurses asking intrusive questions or making them feel as if they came to the clinic “too much” for condom bursts, STI screens, and other sex-related services. A few participants acknowledged circumstances in which they might need to disclose certain information such as their occupation or experiencing homelessness, particularly when it might influence their diagnosis or treatment. However, they agreed that, if necessary, they would likely disclose this personal information to doctors only, as they were typically more respectful and understanding. There was also a discussion of the importance of reporting such mistreatment if there were to be any hope of changing the situation in the future.

*Recommendations for implementation:*

*It is recommended that the review of exclusive breastfeeding in the introduction be removed. The activity on identifying healthy foods that immediately follows can function as an appropriate introductory exercise on its own. Exclusive breastfeeding will be mentioned yet again during presentation of the weaning timeline. In this instance, the benefit of discussing this concept again may be maximized by focusing on how the weaning timeline might differ for women who are HIV-positive. Language around recommendations to breastfeed until children are two years of age should be updated to be more reflective of the many women who are unable to continue breastfeeding for this entire period. It should nonetheless continue to articulate the utility and benefits of exclusive breastfeeding.*

*While women did an excellent job of listing healthy foods as well as resources for finding these foods at affordable prices, provision of a list of some local resources would be beneficial.*

*Another idea that came up during piloting, as noted in field notes, was that of creating a mothers' cookbook, with participants sharing favorite healthy recipes. This should be included as an additional, optional activity.*

*Field notes indicate that SWEAT peer educators found budgeting worksheets helpful and expressed interest in sharing these among a wider group of SWEAT service users. Completing these individually seemed to be an important component, as women had widely varying incomes and expenditures. In order to create a comfortable environment for discussion, it is strongly recommended that this component remain unchanged, though group discussion is to be encouraged.*

*Information on grant eligibility and application should be updated to reflect feedback given by program participants. Additional information on how to obtain documentation without the mother's birth certificate should be included as an optional addition to curriculum materials. The presence of a guest facilitator (from SASSA, Social Development, or Home Affairs) to assist with process-related questions for obtaining documentation or grants is recommended where feasible.*

*The discussion on disclosure of personal information and associations with stigmatized attributes (involvement in sex work, homelessness) reinforces the need for activities aimed to empower sex workers and give them the opportunity to practice advocacy skills. This should be integrated into Session 7 or addressed elsewhere in the curriculum materials.*

### ***Session 8: Child Care & Safety***

This session focuses on household and community dangers and strategies for reducing risk, as well as child sexual abuse.

Session 8 Activities:

A. Introduction.....	5 minutes
B. Household Mapping.....	40 minutes
C. Household Accidents.....	8 minutes
D. Community Mapping.....	40 minutes
E. Community Accidents.....	5 minutes
F. Sexual Abuse.....	10 minutes
G. Child Care.....	8 minutes
H. Closing.....	4 minutes

Children’s safety was clearly an important topic for program participants. Numerous survey responses and talking points raised during both focus group discussions support this. Women frequently discussed generally wanting to keep their children safe, as well as the more specific need for a safe space for their children to play, learn, and be cared for. They expressed a desire to hold Saturday classes, or other activities for their children to keep them away from bad influences in their communities.

Both field notes and survey responses indicate a high level of satisfaction with this session. Many participants indicated this topic was a favorite, an area in which they learned something new, or a reason that other mothers might benefit from participating in Mothers for the Future. More than one participant alluded to her plans to change her behavior related to this content area as well, particularly during the final focus group discussion in which many shared ways to keep their homes safer. In a survey response, Participant 7 acknowledged her past mistakes in throwing cigarettes on the floor instead of putting them out in an ashtray and the risk of starting a fire or her child receiving a burn and her plans to make safer choices in the future.

This session began with mothers sharing their dreams for their children’s futures. Responses listed in field notes echo those given in survey responses, centering on education, happiness and health. Mothers shared dreams of their children growing up to be teachers,



doctors, firefighters, pilots, and one mother who wanted her son to help others had aspirations of him becoming a social worker. The facilitator's notes emphasize the differences observed between responses given on the first day of the workshop when mothers were asked to express their dreams for their own futures and those given this day regarding dreams for their children. Participants spoke with less hesitation and greater confidence and willingness on this final day. Though not intended to be the final session of the curriculum, this activity offered an appropriate closing for the purposes of our workshop, as it allowed women to set goals for their children's futures.

### *Household dangers*

Group activities during this session, as in others, took longer than anticipated to organize. This should be accounted for in planning of all sessions involving a significant number of transitions between group work and discussion. The concepts of household and community mapping were new to the majority of the group, and as such instructions given required additional explanation. Drawing also took longer than the time allotted in the curriculum. Asking group members to present their work also seemed to be a useful exercise and mimicked the format often utilized during Creative Spaces offered at SWEAT. Groups did a great job of identifying various potential dangers in the home. At the end of the activity, an extensive list of risks had been compiled; including several that may not be viewed as obviously dangerous. This list may be used to inform expected responses within the curriculum.

### *Household accidents*

Field notes suggest that the discussions on two of the most common household accidents in South Africa – burns and paraffin poisoning – were particularly valuable. Many potentially harmful practices to treat both burns and paraffin poisoning were initially presented by group members during this section. While women offered appropriate solutions for treatment of ingestion of other poisons, such as giving the child milk or water and inducing vomiting, few, if any were aware that these treatments had the potential to cause greater harm in cases of paraffin poisoning. Similarly, with burns, many women suggested the use of home remedies that, in reality could worsen burn damage such as applying toothpaste or butter to the burn. The group’s conversation offered the opportunity to correct misinformation surrounding some of these harmful practices.

### *Community dangers*

The household mapping activity was repeated using dangers in the participants’ communities in place of household items. This activity demonstrated greater variations in responses, as well as in participants’ interpretations of “community.” Grouping women from the same community together seemed to be a helpful suggestion included in the curriculum in that participants could work together to develop realistic maps and solutions to risks that were relevant to each of them. Developing strategies for preventing community accidents proved to be more challenging than those related to household dangers. This may have been due to the fact that challenges in the community often involve factors beyond the mothers’ control, making solutions less straightforward. Substances and alcohol were a common theme in this session’s notes, as well as in focus group discussions, with mothers expressing concerns about the influence of other community members and the temptations and dangers presented by local

*shebeens* (taverns). Proposed solutions to these challenges included working together with other parents, talking to community members, reporting dangers in the community, and educating children on safe practices.

### *Child sexual abuse*

Due to time, the section on child sexual abuse was unfortunately not given the attention it deserved. At least one participant made note of this in survey responses, indicating that this topic was one that they believed should have been discussed in greater detail. Concerns over child sexual abuse were also raised during the initial focus group discussion, with one participant sharing her beliefs that it was an issue of greater prevalence in their communities than people may have been aware of due to reluctance to report such abuses. A resource list for reporting abuse was discussed and contact information was distributed to the group, though discussion of additional resources may have been helpful. While the material included in this section may have been covered quickly, this discussion also provided the space for one woman to share her concerns over her daughter's recent behavior. She was fearful that her daughter had been keeping things from her and she did not know if this was a normal symptom of adolescence or if she should be worried that something more serious might have been going on. The group quickly rallied behind her to offer advice, support and a plan for seeking help if she felt it was needed.

### *Recommendations for implementation:*

*Though participants did not provide details as to why this session was rated highly, aside from the clear importance of the topic, the fact that it was a very interactive session with group work and mapping activities may have contributed to its popularity. This hypothesis would*

*provide further justification for the integration of more interactive activities and/or group work in other sessions. This recommendation is also made in the final focus group discussion and on survey responses from two participants.*

*Recommendations for this session include the addition of time for activities that require organization into groups and for drawing activities. Further clarification and instruction for mapping exercises should also be provided. Lists of potential dangers in the household and in the communities generated during the session should be used to inform anticipated responses within the curriculum materials.*

*Additionally, the importance of child sexual abuse as a topic may merit providing for additional time for this activity. Further discussion of warning signs of child sexual abuse and how to cope when family members are suspected of perpetrating sexual abuse against children should be included. As was demonstrated by one participant's decision to share her own concerns, inclusion of tools for how facilitators should respond in the event that suspected abuse is reported would be advantageous as well.*

### ***General Comments and Recommendations***

Several noteworthy observations were made throughout the curriculum and pilot sessions. First, the name *Mothers for the Future* has been modified from *Mothers of the Future* in the original curriculum developed by Ms. Nelson, per the request of the program coordinator, who felt that *Mothers for the Future* more accurately described the sentiment and goals of the program.

#### ***Timing***

Secondly, as is generally customary during meetings at SWEAT, short mid-point breaks should be incorporated into the curriculum sessions when possible. It is recommended that

Mothers for the Future sessions not be scheduled for days when participants are also attending other meetings at SWEAT. As some sessions are long and can be intensive, it was noted that attention may run short if participants have already been on site for several hours and are anxious to get back to work, their children or other obligations. Participants should also be notified ahead of time, when possible, if sessions are expected to run longer than two hours so that they may plan accordingly. Within the curriculum there are several suggested restrictions for response times for questions. While some restrictions may be necessary, facilitators should weigh the pros and cons of allowing for additional time for valuable dialogue, if this comes at the cost of having to cut other activities short or extend the session length.

### Language

Several issues related to language used in the curriculum were noted. In light of the varying English-language capabilities of participants, language must be simple to understand. The existing materials do an excellent job of refraining from using complex language. However, this should not come at the cost of providing additional information that might be pertinent to the participants' understanding of a concept. Women were generally curious to know more and to grasp the rationale or importance of many concepts presented. Correct names of medications, anatomical parts, processes, et cetera should be provided whenever possible to cater to the interests of more advanced learners and to build capacity of those with more basic levels of baseline knowledge/English-language skills. Additionally, whenever possible, questions to the group should be framed in an empowering way (e.g. rather than, "Does anyone know what \_\_\_\_ is?" offer: "Would someone like to tell me about \_\_\_\_?") or in a manner that best elicits engagement from the group.

### *Facilitator Ease of Use*

In order to facilitate use of the curriculum materials, it would be helpful to include a set of anticipated questions for each section so that the facilitator may prepare additional resources as needed. Similarly, it would be advantageous to include additional facts or details that could be shared with groups who have more advanced knowledge of the topics being discussed in order to improve engagement. Questions or talking points that the facilitator should address with the group should be bolded or differentiated from the text in some way to help the facilitator locate their place within the session.

### ***Summary of Revisions***

The final curriculum will consist of ten sessions. *Session 2* will be divided into two separate sessions to allow for increased time on each topic. Timing in the remainder of the sessions will be adapted to accommodate for transitions between activities and/or activities that are anticipated to generate lengthier discussions, based on pilot findings. Each session will be adapted to include additional facilitator notes where indicated, optional information to be shared with higher-level learners, and a list of anticipated questions to allow facilitators to gather additional resources prior to facilitation of the session. Language and instructions will be clarified and modified to reflect the local vernacular. Additionally, where appropriate, the facilitator's script will be revised so as to maximize group engagement by posing questions to participants prior to having facilitators supply answers. Aforementioned recommendations for revision have been incorporated into the original curriculum and will be delivered to SWEAT for implementation.

## ***Additional Findings and Recommendations Beyond the Scope of the Curriculum***

### *Space for the Children*

Several other needs of the program participants were identified over the course of the piloting and assessment of the curriculum. In both focus group discussions and survey responses, women expressed the need for a space for their children to learn and play. This was primarily discussed in three different formats – crèches, Saturday classes, and group outings. Many desired a crèche onsite that could be held during the Mothers for the Future meetings. Women often bring their young children to meetings, which can cause distraction to the individual or the group. In order to allow mothers to gain maximum benefit from participation, it would be ideal if the children could be cared for separately. In this way, educational and play activities could be organized for the children as well, so that they too are receiving stimulation and may benefit from attending SWEAT. However, at this time limited availability of human resources for childcare, space, and funding for children's toys and learning tools present barriers to introducing an onsite crèche.

The second option, discussed during focus groups, was the development of a program specifically for the older children of sex workers to come to SWEAT to learn on Saturdays. Women believed this would be a valuable opportunity to allow their children to focus on learning English and other topics and to engage with other children outside of their own communities. They also viewed this as a way to allow for positive social interaction to help combat the courtesy stigma (stigma by association) that many of their children experienced in their schools. Lastly, women thought this would be one way to protect their children from what they viewed as bad influences and dangers in their communities.

Women also expressed the desire to incorporate more fun activities for their children. Women recalled the end of the year holiday party they had with the children, and shared their

memories of the fun they all had. They wanted to organize other activities similar to this and suggested starting monthly outings or field trips for mothers and their children to come together to engage in activities outside of SWEAT. These findings may be best addressed through targeted programming for children or through the Mothers for the Future program's activities outside of the curriculum itself.

### *Counseling*

In survey responses, two women also mentioned the need for counseling services. One woman believed that all of the mothers could benefit from counseling, particularly due to the large number dealing with substance use. Another specifically mentioned child psychology to help her child who was struggling in school. This latter finding may be addressed through future plans that SWEAT has to develop programming that targets the needs of children.

### *Financial Security and Maternity Leave*

Another need that the women expressed was a mechanism to provide financial support to women and their families during times of need. During focus groups, this was discussed in terms of the mothers contributing to a fund that could be used to support children's education during the illness or after the death of a colleague. This fund was also meant to function as a way to provide pregnant sex workers and new mothers with financial support to allow them to take maternity leave. Women expressed concern over their colleagues working on "the road" late into their pregnancies and returning soon after delivery. This would allow mothers to take time off to care for themselves and their infants during the perinatal period. While this finding may be addressed through the Mothers for the Future group, it is outside the scope of the curriculum



itself. It is recommended that the mothers set up something akin to a Village Saving and Loan Association, where participants save money as a group and can take small loans from the pooled funds, to address this need.[34]

*“I wish as we mothers, we are not mothers for, only for us, but as a core group of mothers for the for for whole South Africa, to make ourself and prepare ourselves to have the moment of maternity leave. By our own saving, and helping each other.”* (Participant 15, FGD1)

## **CHAPTER 5: DISCUSSION**

As demonstrated through the literature review, several published works explore the experiences of sex workers who are mothers or support the effectiveness of community empowerment approaches in addressing sex workers’ sexual health. However, there is a clear paucity of literature on parenting interventions for mothers who are sex workers utilizing community empowerment approaches, or otherwise.

Kerrigan’s meta-analysis demonstrated significant impacts of community-based approaches on condom use and HIV prevalence, while established programs such as Sonagachi have demonstrated additional impact on outcomes ranging from individual self-efficacy to financial security and broader social change. These studies suggest that community empowerment approaches may also prove beneficial in addressing other concerns relevant to sex worker communities, such as coping with challenges associated with parenting and increasing sex workers’ self-efficacy as mothers and caregivers. While none of the African projects reviewed in the Moore article had progressed through the final stage on the continuum outlined

by the Ashodaya framework for community empowerment, SWEAT was discussed as one of few who came close to working through engagement and involvement to the final stages of shifting ownership to sex workers.[14] This may place SWEAT in the unique position to continue to forge ahead as a model for community empowerment in the Sub-Saharan African context by widening the scope of their projects and continuing to transition diverse organizational and leadership roles to community members.

Additionally, to the best of our knowledge, no other parenting curricula designed specifically for sex workers who are mothers are currently in existence in South Africa or elsewhere.[13] This further primes SWEAT to stand as a leader in programmatic work targeting the psychosocial needs of female sex workers to support them in their diverse roles as mothers. This educational intervention is intended not only to provide support, but also to empower women to embrace healthy practices through increased knowledge regarding health and childcare, greater self-efficacy in their abilities as parents, peer educators, and advocates for sex worker rights.[13] In the true spirit of community empowerment approaches, Mothers for the Future “aims to challenge health-related vulnerabilities of sex workers who are mothers and their children by providing health information via transformative communication that is developed, led, and sustained by the sex workers themselves.”[13, p. 59, 30]

Findings from this assessment suggest that through *Mothers for the Future*, SWEAT is poised to accomplish these aims. Participants spoke highly of the support they provided one another and expressed confidence gained through sharing their experiences in the safe space they had created. Throughout the workshop, women engaged with the topics presented to seek information they felt would be most useful to them as sex workers and as mothers and displayed their desire to work together and to share what they had learned with their peers. Some noted

personal changes over the course of the program, while still others hinted at behavior changes they had begun to make, which they felt made them better parents.

Given the demonstrated need for interventions of this kind, if proven successful through more formal evaluation, Mothers for the Future has the potential to impact mothers who are sex workers, their children, and their communities across South Africa, as well as internationally. Support from existing evidence and preliminary qualitative findings from this assessment suggest significant potential for proximate impact on mothers' abilities to cope with occupational vulnerabilities related to parenting and sex work through opportunities for increased support and self-efficacy offered by the program.[23, 25] It is also conceivable, based on successes of similar approaches, that in combination with delivery of content on sexual, reproductive, and child health, the curriculum will raise awareness and influence health-seeking behavior, contributing to a wide range of possible long-term health outcomes including reductions in STIs, new HIV infections among women and their children, and unintended pregnancy, in addition to improved outcomes related to pregnancy and childhood illnesses.[14, 26-28] In order to ascertain changes in long-term health outcomes, rigorous longitudinal evaluation will need to be conducted.

Following recommendations of the original author, Ms. Nelson, the curriculum was pilot-tested at SWEAT headquarters in Cape Town for the purpose of assessment and iterative design that should allow for maximized success in program implementation and impact.[13] Equipped with findings of this assessment and resulting evidence-based curriculum improvements, SWEAT has imminent plans to pilot the *Mothers for the Future* curriculum in two additional provinces and to eventually take the program to scale across South Africa. Formal pilot testing, assessment and revision of the curriculum materials will benefit SWEAT as they begin implementation on a wider scale, as participant satisfaction and acceptability will have been

verified, gaps in content will have been minimized, and anticipated challenges to implementation will have been mitigated to the extent possible.

Specifically, undertaking this assessment has allowed us to identify areas in which the curriculum should be modified to improve both participant and facilitator experiences during future implementation. Piloting the modules with members of the intended target audience afforded us the opportunity to gauge participants' familiarity with information provided, to assess which concepts were more difficult to understand, and which topics generated the most discussion. Findings such as these provided valuable information regarding where more detailed explanation, simplification of language, or additional time was required. Revisions to the curriculum made through this special studies project seek to improve clarity of language and re-allocate activities times based on these findings. Where indicated, additional explanation of concepts and activities will be written directly into the curriculum. Supplemental information that may be beneficial to the facilitator or that may be appropriate to share with groups demonstrating higher baseline knowledge have been written into the curriculum as optional sections to read aloud to participants. Gaps in content, as identified through participant feedback and questions, have been primarily addressed in two ways in the revised curriculum. Significant gaps have been resolved through the addition of new activities, while more minor potential gaps have been addressed through the inclusion of anticipated questions for facilitators in each section. The latter will allow facilitators to prepare supplemental information and resources prior to delivering a session, as needed, without adding substantial length to curriculum modules. The pilot also informed us of challenges that might prevent activities from being carried out as intended in the curriculum; whether due to logistics, availability of resources, desires of SWEAT staff, or complex instructions. Again, these findings have allowed us to make changes that aim to

ameliorate these expected threats to successful program delivery, by offering alternatives that may be more appropriate to the context. With the revised curriculum in hand, SWEAT will be better prepared to empower participants to engage with the program and to make it their own.

Finally, findings from this assessment may, in turn, be used to provide a proof of concept for the *Mothers for the Future* program and curriculum, should SWEAT desire to share their program model with other organizations seeking to improve the health and wellbeing of sex workers and their children in their communities. Furthermore, ability to demonstrate proof of concept could position *Mothers for the Future* to function as a landmark parenting intervention for mothers who are sex workers.

### Limitations

In anticipation of the *Mothers for the Future* curriculum being delivered to wider audiences, several limitations should be mentioned. As indicated during the initial development of the curriculum, concepts or evaluation findings may not be entirely generalizable to other sex worker populations.[13] Variance in socioeconomic status, education and literacy levels, social norms and structural and environmental factors will influence acceptability of the curriculum to participants and participants' ability to understand and relate to concepts described in the materials. Within South Africa alone, the diversity of languages and ethnic groups, differences from one province to another, and disparities between rural and urban environments are likely to impact sex workers' beliefs, cultural practices, and lived experiences. These differences may introduce additional challenges to implementation or create unique, context-specific needs that may not be addressed through the current curriculum materials. As such, piloting curriculum

sessions is recommended in each setting in which they will be delivered in order to incorporate nuances in information, language, and particular needs of those populations.

Many of the participants who engaged in the piloting and assessment of this curriculum were long-time service users of SWEAT. This may have given them a greater level of pre-pilot exposure to many of the concepts covered in the curriculum materials than other potential participants, as some of the content areas might be discussed as part of SWEAT's regular programming. This may be particularly true of those mothers who participated in the 2014 pilot. This first cohort of Mothers for the Future participants had exposure to a variety of sessions led by expert guest facilitators that covered many of the same topics as those presented in Nelson's curriculum, making overlaps in content during the two periods likely.

Language may also present limitations to program effectiveness. Women participating in the pilot demonstrated varying levels of comfort with concepts as discussed in English, which may have influenced their comprehension of the content and/or ability to engage. During the final focus group discussion, several women stated that they would feel comfortable delivering curriculum sessions to peers, provided they had access to materials in their preferred language. This finding has implications for delivery on a wider scale, particularly if SWEAT aims to utilize peer facilitation for future delivery of the curriculum of if plans include program expansion to community groups with lower levels of English competency. In the future, this may necessitate translation into other prominent South African languages, such as Afrikaans and Xhosa. Maintaining the ability to further adapt the curriculum to meet these distinct needs will allow diverse groups to utilize *Mothers for the Future* as a tool for improving the health, wellbeing, and agency of mothers who are sex workers.[13]

Finally, Sessions 1 and 9 were not included in this assessment. *Session 1: Mothers Who Are Sex workers* discusses the ideals of being a “good mother” and the many different forms that being a good mother can take. Challenges to meeting those ideals are also covered, in addition to children’s rights and human rights. None of these topics were identified as gaps in the curriculum and many topics were discussed in other contexts during piloting. Therefore, it is unlikely that the exclusion of this session had a large effect on findings of this assessment. However, it is recommended future piloting include all sessions, so as to provide comprehensive feedback and resulting modifications to the curriculum.

Interestingly, topics included in *Session 9: Teaching Moments* closely mimic the overarching themes that were identified throughout the pilot period. Many of these, including respect and self-esteem, were frequently included among traits that mothers stated that they wanted for their children in survey responses. Positive communication is another topic area that came up through focus group and survey responses in which mothers stated that they had learned to be more patient or to listen to their children instead of shouting. In lieu of actual assessment, these findings demonstrate some level of validation of the content included. However, future piloting should assess the content and processes of these sessions, so as to identify areas for improvement.

<i>Session 1 Activities: Mothers Who are Sex Workers</i>	
H. Introduction.....	25 minutes
I. Traits of a Good Mother.....	30 minutes
J. Children’s Rights.....	20 minutes
K. Challenges of a Good Mother.....	25 minutes
L. Solutions and Closing.....	20 minutes
<i>Session 9 Activities: Teaching Moments Activities</i>	
I. Introduction.....	5 minutes
J. Self-Esteem.....	20 minutes

K. Bonding Activities.....	15 minutes
L. Respect.....	15 minutes
M. Positive Communication.....	30 minutes
N. Conflict.....	25 minutes
O. Healthy Discipline.....	20 minutes
P. Graduation.....	20 minutes

Future Recommendations

Regarding curriculum assessment, while qualitative findings suggest positive impact on participant knowledge, self-efficacy as parents, individual self-esteem, and even behavior, more rigorous evaluation will be required in order to measure long-term effects. Additional quantitative assessment would be recommended to capture retention of curriculum content, while both qualitative and quantitative measures may be employed to gauge lasting changes to behavior and self-esteem or health outcomes. Under ideal settings, it would be valuable to track outcomes related to the health and education of the children of participants, though this may not be feasible for a number of reasons. Generally speaking, as an area on which minimal literature exists, additional research on children of sex workers should be pursued. Findings may help to demonstrate any potential impact of mothers’ participation in parenting interventions, such as Mothers for the Future, on their children. Additionally, research in this area may be used to guide forthcoming programming aimed to target the needs of sex workers’ children, specifically. As this is a program area that SWEAT hopes to expand upon, further formative research on the needs of children specific to their context should also be undertaken.

This assessment has also helped to illuminate several additional programmatic needs that SWEAT may choose to address in conjunction with the Mothers for the Future program. One such need would be the development of a complementary program to provide education and interactive play for participants’ children while mothers attend their meetings. Another would be



to adapt the curriculum to be shared with young women before they become mothers; so that they may use the tools it provides as they plan their families and enter into motherhood. Additionally, the program has the potential to encourage mothers to take on larger roles in advocating for sex workers' rights or in providing home-based care to peers in their communities.

Potentially the first curriculum of its kind, *Mothers for the Future* may also serve as a gateway for future community-empowerment interventions for sex workers beyond SWEAT. As a higher number of women are able to participate in the program, a network of “mothers for the future,” can serve to challenge the occupational hazards and health-related vulnerabilities that sex workers and their children face, the harmful policies that put them at risk, as well as the belief that sex work and motherhood are incompatible identities. In doing so, it is my hope that sex workers will be better able to access their health and human rights, to live without fear of violence or incarceration, and to flourish both as individuals and in their roles as parents.

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# APPENDICES

## APPENDIX I: FOCUS GROUP DISCUSSION GUIDE (1)

### Mothers of the Future Evaluation: Focus Group Discussion Guide for Core Mothers

**Research Question:** What are the strengths, weaknesses, suggestions for improvement, potential impact and participant satisfaction levels of the Mothers of the Future program according to participant experiences?

**Study Population:** Mothers of the Future participants (female service users of SWEAT who have previously participated in the Mothers of the Future program; sex workers who are mothers in Cape Town, South Africa)

Date:

Time Start:

Time End:

Interviewer:

Note Taker:

#### **A. Background**

Thank you all for being here to participate in this focus group discussion today. My name is Jenny Holl. I am student studying public health at Emory University in the United States. Some of you probably remember Kate from last year. I am helping her to get feedback on the Mother of the Future program and I will be doing an evaluation so that we can make the group even better for future mothers and for all of you as you continue to be involved, expand on the skills you have learned, and share your knowledge with other mothers at SWEAT and in your communities.

Today I would like to discuss your opinions on the Mothers of the Future program and your experiences in completing the sessions last year. We would like to know more about how you liked the sessions, what you would change, if anything was difficult to understand, and how you or others might use the information learned and the skills gained while in the program. This will help us to make improvements to the classes so that SWEAT will be better able to meet your specific needs as mothers who are sex workers.

The discussion should last about 1 hour. I would also like to mention that there are no right or wrong answers, I simply want your opinions. You are the experts on this program since you were the first group to participate! I value all of your perspectives and would love to hear as many points of view as possible. Please feel to disagree with someone else in the room and share your personal views, but remember to always be respectful. We want everyone to feel comfortable discussing these topics with the group. Join the discussion whenever you have anything to say, but please only speak one at a time so it's easy to hear everyone.

It is important to mention that all your information will be kept confidential. Your participation is completely voluntary, so you may refuse to answer any questions that make you uncomfortable and/or stop the discussion at any time. If you agree, this interview will be recorded to accurately record your valuable thoughts and opinions. The transcript of the recording will not contain your name or any other

data that could identify you, and it will only be accessed by the researchers participating in the evaluation of this program.

Do you have any questions, comments, or concerns for me at this time?

Do I have your consent to participate in and record this interview?

### **B. Introduction and Warm-up**

Can we start by going around the room and giving our first names, ages, and ages of our children?

#### **Activity:**

Ok, before we begin our discussion, let's spend a few minutes brainstorming some of the things we learned as a group by being a part of Mothers of the Future. These can be things that were discussed in the group, things that might have been new to you or your colleagues, things you learned about yourselves or each other, or anything else you took away from the group.

1. *Great!* What is something that was covered in last year's program that you have since shared with a friend?

### **C. Class Content & Pace**

*Now let's think back to last year's sessions. I'd like to talk about how the group felt about the topics that were covered in the class and how much time was spent on the material.*

2. Which sessions stand out as being the most helpful for sex workers who are mothers?

Probe: Least helpful?

3. How relevant were the topics covered to your lives as sex workers who are mothers?

4. How was the pace of the sessions?

Probe: Generally too fast? Too slow? About right?

5. What topics would you have liked to spend more time on?

Probe: Less time?

### **D. Class Satisfaction**

*Now let's talk about what parts of the program you liked and didn't like.*

6. What did you like most about being a part of the Mothers of the Future program?

7. What didn't you like about the program?

8. Was there anything you felt was missing from the program?

Probe: Anything you would add? Take out?

### **E. Program Impact and Potential**

*Next I'd like us to think about how Mothers of the Future program can help mothers who are sex workers. We can talk about any impact the program has had on you all individually or as a group, how it might benefit others, and how the program could grow to better support mothers who participate.*

9. How might participating in the program impact mothers' lives?

Probe: Have you noticed any changes in yourselves or your group members? (changes in lifestyle, confidence, responsibility, beliefs, behaviors?)

10. In addition to providing a space for you all to share and support each other, part of the goal of Mothers of the Future is to help mothers build on the skills they already have or feel that they need. What skills do you think would be most helpful for mothers who are sex workers to learn moving forward?

11. How do you think Mothers of the Future can support the children of sex workers?

Probe: How could SWEAT best help your children and the children of your colleagues when they come to our space?

### **F. Closing Questions**

*The goal of this discussion today is to make sure that SWEAT can offer mothers the best class sessions possible. I'd like to spend a few minutes hearing your input for how the Mothers of the Future program can be improved to better meet the needs of mothers who are sex workers.*

12. Are there any other recommendations you would make in order to improve the Mothers of the Future program?

13. Thinking ahead, what would you most like to see for the future of the program?

Probe: How can MoF continue to support you and other mothers who are sex workers?

### **F. Wrap-up**

In closing, I'd like to thank you for taking the time to talk with me about your experiences in the Mothers of the Future program. Do you have any last comments or questions?

I greatly appreciate the insights, expertise, and perspectives you have shared during our discussion today as they are invaluable to informing the future of the program. Please feel free to reach out to me if you think of anything else or have additional questions or concerns. Thank you again for speaking with me today!

## APPENDIX II: FOCUS GROUP DISCUSSION GUIDE (2)

### Mothers for the Future Evaluation: Focus Group Discussion Guide

**Question:** What are the strengths, weaknesses, and participant satisfaction levels of the Mothers for the Future program according to participant experiences and how can the program be improved upon?

**Study Population:** Mothers of the Future participants (female clients of SWEAT; sex workers who are mothers in Cape Town, South Africa)

Date:

Time Start:

Time End:

Interviewer:

Note Taker:

#### **A. Background**

Thank you all for agreeing to participate in this focus group discussion. My name is Jenny Holl. I am student studying public health at Emory University in the United States. I am working on an evaluation of the new curriculum that was recently developed for Mothers for the Future.

Today I would like to discuss your opinions on the Mothers for the Future program. Specifically, I'd like to talk about the sessions completed over the past few weeks. We would like to know more about how you liked the sessions, what you would change, if anything was difficult to understand, and how likely you will be to use information you learned and the skills you gained while in the sessions. This will help us to make improvements to the classes so that SWEAT will be better able to meet your specific needs as parents who are sex workers. I'd also like to know a bit about what you see as the greatest needs for your children, your experiences with health care and what role SWEAT might be able to play in any gaps you see around either of these areas.

The discussion should last about 60 minutes. I would also like to mention that there are no right or wrong answers, I simply want your opinions. I value all of your perspectives and would love to hear as many points of view as possible. Please feel to disagree with someone else in the room and share your personal views, but remember to always be respectful. We want everyone to feel comfortable discussing these topics with the group. Join the discussion whenever you have anything to say, but please only speak one at a time so it's easy to hear everyone.

It is important to mention that all your information will be kept confidential. Your participation is completely voluntary, so you may refuse to answer any questions that make you uncomfortable and/or stop the discussion at any time. If you agree, this interview will be recorded to accurately record your valuable thoughts and opinions. The transcript of the

recording will not contain your name or any other data that could identify you, and it will only be accessed by the researchers participating in the evaluation of this program.

Do you have any questions, comments, or concerns for me at this time?

Do I have your consent to participate in this interview?

### **B. Introduction and Warm-up**

1. What is something talked about in our sessions so far that you would want to share with a friend who is both a mother and a sex worker?

2. How was the workshop for you as a group?

### **C. Class Content & Pace**

*Let's talk first about how the group felt about the topics that were covered in the class and how much time was spent on the material.*

3. What from the meetings we've had do you think is most valuable to sex workers who are mothers?

Probe: What information do you think you or your colleagues will be most likely to use/put into practice?

4. How relevant were the topics to your lives as mothers who are sex workers?

5. How realistic were examples/activities used to demonstrate the topics?

6. How has the pace of the sessions/meetings been?

Probe: Too fast? Too slow?

7. What topics would you have liked to spend more time on?

Probe: Less time?

### **D. Class Satisfaction**

*Now let's talk about what parts of the classes you liked and didn't like.*

8. What did you like most from the workshop sessions?

9. What didn't you like about the workshop? Individual sessions?

10. Are there any recommendations you would make in order to improve the workshop sessions?

Probe: Anything that was hard to understand? Anything you felt was missing? Anything you would add? How to make more "practical"? Anything to keep in mind as we move forward?



## **F. The Future of Mothers for the Future**

*The goal of this discussion today is to make sure that SWEAT can offer mothers the best class sessions possible. I'd like to spend a few minutes hearing your input for how the classes and the Mothers for the Future program can be improved to better meet the needs of mothers who are sex workers.*

11. What do you think that mothers can gain from participating in Mothers for the Future?
12. What changes might you make based on what you have learned in the workshop? *Probe: Any changes to how you parent? Any changes to how you access healthcare? Changes to how you make decisions about your healthcare? Health of your children?*
13. What could Mothers for the Future do to better support your children?  
Probe: How could children be involved in the space? What are your greatest needs for your children?
14. Think about if you were to facilitate any of the sessions we have covered. How prepared would you feel to teach your peers about the topics we have covered?  
Probe: What would you need in order to feel more comfortable teaching others? Certain topics you feel need more clarification? What would you do differently as the facilitators?
15. Do you all have any recommendations for Mothers for the Future in general?
16. Anything else you would like to add?

## **G. Wrap-up**

In closing, I'd like to thank you for taking the time to talk with me about your experiences in the Mothers for the Future program. Do you have any last comments or questions?

I greatly appreciate the insights, expertise, and perspectives you have shared during our discussion today as they are invaluable to informing the future of the program. Please feel free to reach out to me if you think of anything else or have additional questions or concerns. Thank you again for speaking with me today!

APPENDIX III: SHORT ANSWER QUESTIONNAIRE  
*[Excerpted from Pre-Post Survey]*

**Mothers of the Future Week 3 Post-Workshop Questionnaire**

27. What did you like most about the Mothers for the Future workshop?

28. Which class or classes did you enjoy the most?

29. What didn't you like about the Mothers for the Future workshop?

30. Which class or classes did you enjoy the least?

31. What would you do differently if we were to do a workshop like this again?

32. Was there anything that was missing from the workshop? (A topic you wish we had talked about, certain kinds of activities, not enough information about certain things, more time for discussion, more interactive activities, anything else...?)

33. Did you learn anything about yourself by doing the workshop? If yes, what?

34. Did you learn anything about your children by doing the workshop? If yes, what?

35. Would you recommend other mothers to participate in Mothers for the Future? Why or why not?

36. What do you want most for your children in the future?

37. In what ways do you think SWEAT could better support you or your children?

Please share any other feedback about the workshop with me so that we can make it better for you and future Mothers of the Future!

## APPENDIX IV: INFORMED CONSENT



### **Consent to Participate in the Piloting and Assessment of the Mothers of the Future Curriculum**

**Title:** *Pilot Assessment of Mothers of the Future Curriculum*

**Principal Investigator:** Gordon Isaacs, PhD (Sex Worker Education and Advocacy Taskforce)

**Co-Investigators:** Jennifer Holl (Emory University)

#### **Introduction**

You are being asked to participate in the piloting and evaluation/assessment of the Mothers of the Future curriculum. Your input will inform our sex worker advocacy efforts for sex workers who are mothers. This form is designed to tell you everything you need to think about before you decide to consent (agree) to participate or not to participate. It is entirely your choice. If you decide to take part, you can change your mind later on and withdraw from the study. You can skip any questions that you do not wish to answer. Participation in this study will be completed over 9 sessions during the next 3 weeks. This study is being conducted as part of our continued efforts to serve the sex work community, including sex workers and their families.

Before making your decision:

- Please carefully read this form or have it read to you
- Please ask questions about anything that is not clear

You can take a copy of this consent form, to keep. Feel free to take your time thinking about whether you would like to participate. By signing this form you will not give up any legal rights.

#### **Study Overview**

The purpose of this study is to pilot test and assess the recently developed Mothers of the Future curriculum in order to improve upon the existing materials for future use.

#### **Procedures**

You will be participating in an assessment which will include short paper-based questionnaire and focus group discussions. You will be asked for your feedback and opinions as well as about your experiences with the curriculum and as a mother. Before beginning the assessment, you will be asked to fill out a short pre-workshop survey. With your permission, the focus group discussions will be taped using an audio recorder. We will again verbally ask for your consent before each recorded session. The recordings will not be shared with anyone other than the Principal and Co-Investigators of this study. The facilitator (Jennifer Holl) will transcribe the interview, and immediately after transcribing the audio recording will be destroyed. You are free to refuse to be audio recorded, in which case handwritten notes will be taken. After the interview, all identifying information will be removed from the notes. All paper notes will be securely stored and will not be shared with anyone other than the Principal and Co-Investigators of this study.

### **Risks and Discomforts**

The only foreseeable risk is a breach of confidentiality. This is *highly unlikely*, as researchers will protect all personally identifiable information with password protected documents and computers, as well as locked filing cabinets (see Confidentiality section below.) There are no other foreseeable risks or discomforts associated with this evaluation.

### **Benefits**

This evaluation will allow SWEAT to pilot test and assess the Mothers for the Future curriculum so that it can be improved for future cohorts of the program. Your input will help us to develop a proven curriculum that will stand as a model for the growth of this program and has the potential to benefit mothers and their children on a much larger scale.

### **Compensation**

You will not be offered payment for being in this evaluation.

### **Confidentiality**

Certain offices and people other than the researchers may look at study records. These offices include supervisory staff at the co-investigators' home institutions (Emory University in Atlanta, GA, USA).

A study number rather than your name will be used on study records wherever possible. Your name and other facts that might point to you will not appear when we present this study or publish its results. All identifying information will be destroyed. Only the principal investigator and co-investigators will have access to participant identities during data collection and interview transcription. Interview recordings will be downloaded only to password-protected computers belonging to the principal investigator or co-investigator and then destroyed upon transcription.

### **Voluntary Participation and Withdrawal from the Study**

You have the right to leave the interview at any time or refuse to answer any question without penalty. This decision will not affect your ability to obtain resources or services from SWEAT.

### **Contact Information**

Jenny Holl at [jennifer.holl@emory.edu](mailto:jennifer.holl@emory.edu) or Dr. Gordon Issacs at [gordon.issacs@sweat.org.za](mailto:gordon.issacs@sweat.org.za) if you have any questions about this evaluation or your part in it or if you have questions, concerns or complaints about the research.

**Consent**

Please, print your name and sign below if you agree to be in this evaluation. By signing this consent form, you will not give up any of your legal rights. We will give you a copy of the consent information, to keep.

\_\_\_\_\_  
Name of Subject

\_\_\_\_\_  
Signature of Subject

\_\_\_\_\_  
Date

\_\_\_\_\_  
Time

\_\_\_\_\_  
Signature of Person Conducting Informed Consent Discussion

\_\_\_\_\_  
Date

\_\_\_\_\_  
Time