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SRH and HIV service integration and stigma

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This **Steps to Integration** series provides a guide on how to integrate HIV and sexual and reproductive health (SRH) services based on findings from the Integra Initiative.

The **Integra Initiative** is a research project on the benefits and costs of a range of models for delivering integrated HIV and SRH services in high and medium HIV prevalence settings, to reduce HIV infection (and associated stigma) and unintended pregnancies. It was managed by the International Planned Parenthood Federation (IPPF) in partnership with the London School of Hygiene & Tropical Medicine (LSHTM) and the Population Council.

Findings from the project show that integrating HIV and SRH services has the potential to:

- ✓ **Increase uptake of health services**
- ✓ **Increase range of services available**
- ✓ **Improve quality of services and efficient use of resources**
- ✓ **Enable health systems to respond to client needs and improve overall client satisfaction**



SRH and HIV service integration and stigma

Introduction

The pervasiveness of HIV-related stigma and discrimination is widely documented. Stigma is a sign of disgrace or shame. It originates from the ancient practice of branding or marking someone who was thought to be “morally flawed” or to have behaved badly and therefore to be avoided by other members of society. Stigma is often described as a process of devaluation. In other words, if one is stigmatized one is discredited, seen as a disgrace and/or perceived to have less value or worth in the eyes of others. Stigma is frequently faced by people living with HIV and those who they are associated with, such as their partner or spouse, children and other members of their household. It is frequently followed by discrimination, which involves treating someone in a different and unjust, unfair or prejudicial manner, based on their real or perceived HIV status.

There are further dimensions to the concept of stigma as it relates to HIV. Stigma can be “felt” or “perceived”, i.e. stem from the individual’s negative self-perceptions and lack of self-worth. Perceived stigma can be inferred from another individual’s actions (whether or not they intentionally stigmatize the person), or presumed or feared based on the person living with HIV’s own insecurity. Stigma can also be “enacted,” that is to say, the actual discriminatory behaviour of others, which can come from family, friends, community

members, or health providers. These two scales of experience overlap and are experienced differently in different settings, contributing to the multifaceted challenge of addressing HIV-related stigma in health programmes.

The Integra Initiative sought to explore the experience of stigma of clients living with HIV in a variety of settings, both service-based (when seeking family planning, antenatal, and postnatal care services) and facility-based (when seeking services in different facility types).

There is a complex relationship between stigma and service integration. In some cases, integration has been shown to reduce stigma by providing HIV service clients the anonymity of attending a facility that offers a range of service, i.e. they can “blend in”. Yet in many other circumstances, clients attending HIV services at integrated or partially-integrated clinics have perceived an increase in stigma or in the risk of stigma due to factors such as non-confidential staff practices.¹ The relationship is further complicated by the relative nature of stigma; what is experienced by one group of people in one setting is likely to be felt differently in a different setting, or by a different group of people. Integra sought to tease out this relationship and extract lessons that can inform strategic integration programme design that capitalizes on the potential benefits of integration to reduce stigma, while also avoiding the potentiality of integration to increase stigma.



Several overarching questions characterized Integra research into what contributes to the experience of stigma. What behaviours or circumstances cause women living with HIV to feel stigmatized? In what health facilities do they experience what kind of stigma? What kind of stigma do they experience when seeking health services other than for HIV?

In seeking SRH services (specifically, antenatal care, postnatal care, and family planning services) at facilities in Kenya, it was found that women experienced very little enacted stigma – that is to say, discriminatory or malicious behaviour on the part of health providers and facility staff. Rather, women reported experiencing significant perceived stigma – fear that their status would be “outed” to other facility clients or providers, and that this would result in discriminatory behaviour from the community, family and friends. Indeed, the primary source of enacted stigma that women reported experiencing was abandonment by their husband or partner when the woman’s HIV-positive status was revealed (through either intentional or involuntary disclosure).ⁱ Many women noted that they specifically sought a facility that was farther from home despite the added expense of travel because they were less likely to encounter someone they knew.^{iv}

Facility-based factors that contributed to perceived stigma or fear of being “outed” included:

- inadequate facility infrastructure (e.g. group waiting rooms in which HIV clients risk being identified by having brightly coloured antiretroviral (ARV) cards, obvious food parcels, and non-discrete ARV disbursement at the pharmacy);
- seeing a different provider with each visit and having to re-reveal and re-explain one’s HIV status; and
- provider indiscretion around family members who accompany the client for purposes of the SRH visit (e.g. giving the baby ARV medication during a postnatal care visit).^{i, iii}

The perception of stigma is important whether or not women actually experienced the enacted stigma they feared. Fear of stigma was perhaps the most influential factor at play in terms of women’s facility preference as well as on her behaviour – fear of stigma reduces willingness to disclose status, negatively impacts on breastfeeding practices, and makes adhering to ARV treatment stressful.ⁱ The Kenya studies indicated that most women feared their family, friends and partner discovering their HIV status, and had a correspondingly low disclosure rate due to this perceived stigma. This desire for secrecy contributed to the women wanting more confidential services and fearing the possibility of being “outed” through disorganization or carelessness in an integrated facility. Accordingly, women tended to prefer seeking services at a stand-alone HIV clinic, where they felt that their status was more protected in an environment where all clients had similar desires for discretion.ⁱ



Stigma and seeking HIV services at different types of facilities

The question of relative stigma at different types of facilities that specifically served HIV clients was also explored by the Integra Initiative. Integra assessed the experience of stigma by women seeking HIV services in Swaziland at stand-alone facilities, partially stand-alone facilities, integrated facilities, and partially-integrated facilities.

The relationship between the type of integration model, privacy and fear of status exposure was complex.ⁱⁱⁱ Women often preferred stand-alone facilities both because they offered a higher quality of HIV services, and because they were perceived to offer a more desirably dynamic of confidentiality. Furthermore, women's preference for stand-alone facilities was also rooted in the psychosocial support they gained. In an environment where everyone was HIV-positive, women felt "free" and more comfortable asking questions, soliciting advice, and relating to other clients. As a result of this psychosocial support, women gained increased feelings of self-worth and confidence, and were actually more inclined to disclose their status to their family and friends than women in integrated facilities where inadvertent disclosure was perceived to be more likely. This suggests that although women seek services at stand-alone facility because they are perceived to offer more confidentiality, the women are ultimately more likely in fact to later disclose their status as a result of the comfort conferred by the non-confidentiality among other HIV-positive

clients that they result in. It was clear that the woman's own acceptance of her HIV status influenced how fearful she was of stigma.ⁱⁱⁱ This is one of the dimensions of the shifting scale of stigma which lends additional complexity to understanding how best to address HIV-positive women's needs in multiple circumstances. There were, however, some perceived downfalls to the stand-alone clinics – some women worried that just by arriving at these facilities, any passers-by who might see them would immediately assume they were HIV-positive.

In each of the other clinic types in Swaziland – partially stand-alone (i.e. an HIV service building attached to a main hospital), partially integrated, and fully integrated, women experienced similar fears surrounding forced or inadvertent disclosure of their status, but with fewer of the psychosocial benefits gained from stand-alone clinics.ⁱⁱⁱ In each of these environments, the general trend was that disorganized physical infrastructure, inadequate integration training of facility staff, and poorly-managed confidentiality procedures lead to a greater proportion of perceived stigma.ⁱⁱⁱ Yet despite the variances in perceived stigma in each of the four facility types, it is notable that in each scenario Integra explored (whether women were seeking SRH or HIV service, and no matter the setting), women's fear of stigma did not impact their uptake or adherence to ARV treatment; most women cited the desire to live and care for their children as an overwhelming motivator.^{i, iii}



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Recommendations

Evidence from the Integra Initiative reveals how complex and delicate the issue of stigma is as it relates to providing integrated HIV and SRH services. How can we keep the stigma-reduction gains of integration (the confidentiality gained by blending in with other services) but reduce the possible increases in stigma that can happen with integration? Most abundantly clear were several points:

- Fear of stigma is highly influential to women's health-seeking practices; it is therefore critical to **create practices that protect women's confidentiality**, as well as making this discretion clear to clients and the community.
- **Precisely-strategized confidentiality policies and skilled management of the integration process** are critical for a successful integration programme that does not increase either perceived or enacted stigma.
- **The psychosocial support unique to stand-alone facilities is a valuable service that should, if possible, be included** in the integration programme design so that HIV-positive clients can still benefit from this even at an integrated facility. Whether or not this is done, provider training on counseling on disclosure must be improved, and client decisions on disclosure should be fully respected.
- **Improve provider training overall regarding HIV client interaction.** This includes ensuring provider friendliness, non-discrimination, openness to questions and confidentiality practices.

- **Improve subtlety of labeling client records, ARV cards, and food distribution** so that possessing any of these does not clearly expose a patient as being at a clinic to receive HIV services.
- Frequently changing providers at an integrated facility increases perceived stigma or fear of stigma. Therefore, endeavor to either **limit the providers who offer integrated services, or improve confidential record keeping** to reduce the number of times a client has to explain their condition.

Interestingly, considering that a goal of reducing perceived stigma at integrated facilities is that women are better able to conceal their HIV status, it seems somewhat incongruous that the benefits to be gained from stand-alone centers (the psychosocial support that improves women's confidence and willingness to disclose) would subsequently defeat the need for a confidential environment in the first place. However, gaining confidence and an improved sense of self-worth is an ongoing process that takes time, and occurs at different paces for different individuals. Vigilant confidentiality at integrated centers would benefit women who are not as far along the self-acceptance and disclosure route, and continue to benefit even those who are accepting of their status.



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