STRENGTHENING THE CONTINUUM OF CARE FOR FISTULA PREVENTION AND REPAIR IN ETHIOPIA

An estimated 37,500 Ethiopian women are living with untreated obstetric fistula, a devastating childbirth injury that results in chronic urinary and/or fecal incontinence. Affected women and adolescents are often abandoned by their partners and families, ostracized by their communities, relegated to separate living spaces, and subjected to profound stigma and discrimination. As part of its mandate, the USAID-funded Integrated Family Health Program (IFHP), jointly implemented by Pathfinder International and John Snow, Inc. (JSI), supports regional, zonal, and woreda (district) health offices to build and fortify a comprehensive continuum of care to address fistula in its four program regions—Amhara, Oromia, Tigray, and Southern Nations, Nationalities, and People’s Region. This technical brief explores IFHP’s approach, implementation experience, and lessons learned.
Context

With 3,500 new cases occurring each year,* Ethiopia is among a handful of countries across the northern half of sub-Saharan Africa extending into pockets of the Middle East and Asia that together constitute the “fistula belt.” In these high-burden countries, the vast majority of fistula cases are caused by prolonged, obstructed labor.† The continuous pressure exerted on the vaginal wall leads to decreased circulation and breakdown of vaginal tissue. Over time, the tissue gives way, leaving a hole through which urine or stool leak uncontrollably.

Delivering with skilled birth attendance and access to emergency obstetric care are the most effective ways to avert fistula.‡ In Ethiopia, structural barriers, such as distance to the health facility and transportation costs—further compounded by sociocultural preferences for home birth—limit access to and uptake of services. In this environment, just to percent of women deliver with skilled birth attendance, although recent Federal Ministry of Health data indicate that this figure is growing.‡

While the direct cause of fistula is straightforward, a more nuanced web of indirect factors also feature on the causal pathway. Although many of these factors are biological in origin (e.g., short stature, a large fetus), others are sociocultural and, therefore, more amenable to change. For example, early marriage and the immediate initiation of childbearing is associated with fistula development.‡ Despite Ethiopian legislation prohibiting marriage before age 18, the median age at first marriage is 16.5 years, and 34 percent of women aged 15–49 have given birth by the age of 18.§ Unequal gender norms perpetuate these underlying factors, and limit women’s agency, mobility, and capacity to seek care.

IFHP Strategy and Implementation

A comprehensive fistula response necessitates a continuum of care focusing not only on repair and treatment services, but also on the complex social dimensions of fistula. Affected women and adolescents face profound stigma and isolation. Limited awareness of the etiology of fistula breeds misconceptions (e.g., that the condition is a punishment for sin or is a sexually transmitted infection), further discouraging care-seeking and exacerbating stigma. These social dimensions render affected women and adolescents particularly hard to reach, and warrant targeted community-based interventions.

For decades, an established network of fistula treatment centers associated with Hamlin Fistula Ethiopia (HFE) and Women and Health Alliance International (WAHA/UNFPA) have provided surgical fistula repair and rehabilitation. However, the absence of complementary, community-based interventions capable of navigating the social dimensions of fistula has resulted in significant gaps in prevention, case identification, and postoperative care and follow-up. Moreover, a substantial backlog of cases has amassed. For these women, repair is usually a more complex procedure due to extensive vaginal scarring.

Working closely with the Ministry of Women, Children, and Youth Affairs, health extension workers (HEWs),† local women’s associations, and regional, zonal, and woreda health offices, IFHP strives to bridge these gaps by bundling existing clinical services into a continuum of care that also incorporates community-based interventions for preventing fistula, identifying

* Efforts to calculate incidence and prevalence are complicated by the scarcity of reliable data, difficulty of identifying cases, and challenges associated with fistula diagnosis. Consequently, estimates vary widely. In 2003, the Campaign to End Fistula reported that in Ethiopia, 9,000 new cases occur each year and as many as 100,000 women are living with untreated fistula; however, the 2005 Ethiopia Demographic and Health Survey suggested that these figures may be inflated, and estimated that 36–39,000 women are living with untreated fistula with 3,500 new cases per year.
† HEWs are a cadre of frontline health workers who provide preventive and basic curative health services within communities.
‡ Although recent Federal Ministry of Health data indicate that this figure is growing.
§ The medium age at first marriage is 16.5 years, and 34 percent of women aged 15–49 have given birth by the age of 18.
cases, and supporting survivors. As shown in Figure 1, community sensitization to increase awareness and transform norms is woven throughout the continuum, and serves to de-stigmatize fistula and foster a more enabling environment for case identification, care-seeking, and acceptance of survivors.

The following sections discuss the three components of the continuum model that IFHP directly supports: bolstering prevention efforts, improving case identification and patient flow, and supporting survivors to reintegrate into their communities. Repair and treatment services—the third component of the continuum—are provided by HFE and WAHA/UNFPA, and as such, are not discussed in detail.

Bolstering prevention efforts
Early initiation of childbearing is associated with fistula development in Ethiopia. To delay pregnancy, IFHP collaborates with woreda-level Women, Children, and Youth Affairs offices and local organizations in program regions where early marriage is prevalent (Amhara and Tigray) to establish or strengthen community-based committees that uphold Ethiopia’s law prohibiting marriage before the age of 18. Cancellation committees investigate suspected early marriages and sensitize the families involved on the consequences of early marriage and the benefits of cancelation. This approach enables adolescents to delay childbearing, and also spurs broader community dialogue and reflection on early marriage. Moreover, because adolescents are typically barred from completing their education once married, cancelation allows them to finish school and reap the socioeconomic and health benefits associated with education. These efforts, along with continuous engagement with religious and community leaders, have resulted in the cancelation of 13,490 early marriages in these two regions since 2008.

Recognizing the importance of skilled birth attendance for fistula prevention, IFHP also provides intensive support to 33 woredas to increase access, quality, and acceptability of maternal health services. The program works closely with woreda health offices to build the capacity of midwives and health workers to provide basic emergency obstetric care, and facilitates regular community meetings to identify specific barriers to care and create tailored solutions. The proportion of women delivering with skilled birth attendance in the intervention woredas has subsequently increased from 7 percent (in 2008) to 36 percent (in 2013). Finally, in all four program regions, IFHP works with regional and woreda health offices to expand contraceptive access and uptake, enabling healthy timing and spacing of pregnancies, and contributing to improved maternal health outcomes.

Improving case identification and patient flow
Due to limited awareness of treatment availability and pervasive stigma, case identification has historically been a critical barrier to enrolling affected women and adolescents in care. IFHP supports woreda health offices in its four program regions to train HEWs on fistula case identification, and concurrently trains community and religious leaders, local women’s associations, and fistula survivors to engage in active case finding. The training covers signs and symptoms of fistula, relevant screening questions, and appropriate strategies for engaging with families of affected women and adolescents.

The number of cases identified has steadily increased throughout the project. In 2009, just 277 suspected cases of fistula were identified and referred; however, as community sensitization and mobilization efforts began to take root, the program successfully scaled up, and from 2009 to 2010, the number of cases identified and referred more than doubled (from 277 to 672). The program saw another 50 percent increase in the following year (from 672 in 2010 to 1,011 in 2011). Since 2011, case identification has stabilized, averaging 935 cases per year.

Although no population-based study has been conducted, observational evidence from treatment facilities suggests a decline in the backlog of cases, as patients enrolled in care are reporting a shorter lag time between the onset of symptoms and the decision to seek care. While these assessments are not robust enough to support causal inferences, they do point to the possibility of a gradual shift in attitudes and norms, indicating that communities may be fostering a more enabling environment for case identification and care-seeking.

Once cases are identified, affected women and adolescents encounter further barriers to care, such as distance to the treatment facility, prohibitive costs of transportation, and hesitation among bus drivers to allow onboard a woman who is leaking urine or stool. IFHP facilitates treatment by transporting clusters of suspected cases and accompanying relatives to treatment facilities.

Responding to an observed inefficiency, IFHP and its health system counterparts restructured the flow of screening and referral services for suspected fistula cases in 2011. A review of program data revealed that a non-trivial proportion of women were being erroneously
identified as fistula cases and transported long distances to tertiary facilities, only to discover that the underlying cause of their incontinence was not fistula. In response, IFHP began working with worsteda health offices to train service providers at lower-level health centers to better screen for and diagnose fistula. All suspected cases are now first taken to a closer, primary health care unit for an initial screening, and true cases are referred to tertiary facilities for treatment. Since 2011, IFHP has trained 295 lower-level providers to screen for and diagnose fistula. The proportion of false positives receiving a diagnosis at tertiary facilities has declined significantly during the project—from 34 percent in 2009 to 6 percent in 2013 (see Figure 2).

Supporting survivor reintegration

Following repair and rehabilitation, survivors are susceptible to myriad negative physical and psychological effects, such as rupture, stress incontinence, infection, genital ulceration, infertility, and depression. For each cohort of fistula survivors, IFHP facilitates a life skills training focused on decision making, values clarification, partner negotiation, and healthy behaviors. Survivors are also educated on infection prevention, and provided with sanitary materials and hygiene products. Recognizing that survivors are a heterogeneous group with diverse needs, IFHP uses a target-segmented approach to ensure the most vulnerable women and adolescents receive additional support. For these women, IFHP dispenses seed money and training on initiating income-generating activities. Finally, 5–10 willing women from each cohort are selected and trained as Fistula Ambassadors. Upon return, these women educate their communities on fistula prevention, availability of treatment, and the ramifications of early marriage and gender inequality.

Lessons Learned

Roughly 3 in 10 survivors require ongoing, regular care and follow-up; however, ensuring postoperative, community-based follow-up and support for survivors has proven challenging. The program is currently devising ways to strengthen ties with treatment facilities to better link HEWs with survivors in their respective communities and facilitate targeted care for those with greater needs during rehabilitation. IFHP is also beginning to create individually tailored reintegration plans specific to each survivor’s socioeconomic profile, taking into account her family background, economic status, and social capital.

In addition, the program identified a major gap in clinical services available for women experiencing pelvic floor disorders that also cause urinary incontinence, such as utero-vaginal prolapse. IFHP is currently conducting a rapid assessment to determine ways to address this gap, and will use findings to address the needs of this underserved population.

Next Steps

The Federal Ministry of Health recently set a goal to achieve fistula elimination by 2020. Recognizing its technical leadership, the Ministry requested that IFHP join the Fistula Elimination Task Force and share best practices for community-based interventions. Through its work at the national, regional, and woreda levels, IFHP continues to strengthen the continuum of care and build the capacity of communities to support fistula elimination.

ENDNOTES

6 Central Statistical Agency (Ethiopia) and ICF International, 2012.
7 Tollosa and Asnake, 2013.