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Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health

"[Obstetric fistula is] a stark outcome of gender inequalities, the denial of human rights and poor access to reproductive health services" (UN Secretary-General, Report A/71/306, 2016).

"The persistence of fistula is a result of human rights denied and a reflection of human rights abuse" (Babatunde Osotimehin, Executive Director, UNFPA, 2016).

Executive summary

Obstetric fistula is a devastating but easily preventable childbirth injury caused by prolonged, obstructed labour. At present it affects around two million women, mostly in sub-Saharan Africa and Asia. Obstetric fistula can cause both urinary and faecal incontinence, as well as often resulting in psychosocial (mental health) difficulties, mobility impairment (in about 20% of cases) and a host of adverse economic and social consequences, including stigmatisation and isolation from families and communities, and lack of development.

The denial of human rights is both cause and consequence of obstetric fistula. Poverty is the main underlying cause. Younger, poorer, less well-educated, first-time mothers living in rural parts of developing or emerging countries – or women whose lives encompass any or most of these factors – are the most likely to develop the condition, especially in societies in which the views of men, or traditional healers, are likely to trump those of women in childbirth.

Most attention to date has focussed on achieving surgical repair. The serious psychosocial effects of obstetric fistula, the need for community education and reintegration and, critically, human rights-based prevention strategies and actions, have received less attention, as has the role of men, and the status of women with fistula as people with disabilities. Even in the area of repair, progress is slow. Most women who endure obstetric fistula today will die without receiving the necessary surgery.

The withdrawal of US Government funding from UNFPA threatens to weaken the situation further. Given the extent of obstetric fistula and its devastating effects on women, in the light of the SDGs and in clear recognition of the condition as a human rights abuse, this paper urges the Special Rapporteur and the Human Rights Council to assume vigorous and determined leadership on this issue, and for ensuring that affected States are both supported and held to account for their actions to eradicate it.

The purpose of this paper

The continued existence of obstetric fistula, affecting more than two million women worldwide, is an affront to the achievement of women's human rights in the countries in which it mostly occurs. The denial of human rights is both cause and consequence of obstetric fistula, yet most attention to date has focussed on achieving medical repair. Even so, progress has been slow and most women who endure this condition today will die without the necessary surgery. The effect, on the lives on the women, on the communities in which they live, is devastating.

Since 2003, the under-resourced international Campaign to End Fistula has been led by UNFPA. The recent withdrawal of funding from UNFPA by the US Government threatens to weaken action still further. Given the extent of obstetric fistula and its devastating effects on women, in the light of the SDGs and in clear recognition of the condition as a human rights abuse, this paper urges the Special Rapporteur and the Human Rights Council to assume vigorous and determined leadership on this issue, and for ensuring that affected States are both supported and held to account for their actions to eradicate it.

The extent of the issue

"It is difficult to walk. You feel like your thighs are on fire. You can't travel. It is so uncomfortable when you sleep. You can't work because you are in pain; you are always wet and washing clothes…You cannot eat comfortably because you fear the urine will be too much. It hurt so much I thought I should die" (Kenyan woman, quoted in Odhiambo, Agnes, Kenya: When Childbirth Leads to Disability and Despair, Human Rights Watch, 2013)

Obstetric fistula is a devastating but easily preventable childbirth injury caused by prolonged, obstructed labour. It can cause both urinary and faecal incontinence, as well as often resulting in psychosocial (mental health) difficulties, mobility impairment (in about 20% of cases) and a host of adverse economic and social consequences, including stigmatisation and isolation from families and communities, and lack of development.

Around 85-90% of women who develop fistula deliver stillborn babies, and the woman is often rendered infertile. Physical debilitation, bladder infections and stones, kidney failure, and malnutrition are other common consequences, along with the intensification of poverty due to abandonment and rejection. Surgical repair is fully successful in only about 66% of cases. Research shows that serious medical, psychological and social consequences often persist, even after successful surgical repair. The effect on children, families and communities is huge.

Virtually eradicated in countries with high-quality health systems, obstetric fistula persists in much of sub-Saharan Africa and Asia, especially in countries and communities affected by poverty, in which early marriage and early child-bearing are common. According to the WHO, around two million women and girls are estimated to have fistula, with around 50,000 to 100,000 new cases occurring each year. The WHO reports that the exact number is hard to estimate, "due to a lack of commitment in addressing and resolving this problem" (WHO, 10 Facts on Obstetric Fistula, no date).

Younger, poorer, less well-educated, first-time mothers living in rural parts of developing or emerging countries – or women whose lives encompass any or most of these factors – are the most likely to develop the condition, especially in societies in which the views of men, or traditional healers, are likely to trump those of women in childbirth. Some studies suggest rates of obstetric fistula of 50-80% in women aged less than 20 in certain areas, due to small pelvic size caused by malnutrition, young age at first childbirth, or both.

The UNFPA leads the Campaign to End Fistula, supporting almost half of all surgical repairs in developing and emerging countries, where the lack of systemic and appropriate prenatal and postpartum care contributes to the condition's prevalence. In many places doctors lack the training or resources necessary for conducting repair. According to the Campaign to End Fistula, around 70% of fistula cases remain untreated. Though very welcome, the UNFPA's estimate of 131,000 fistula repairs in total between 2003 and 2012 (with 47,000 supported by the Campaign to End Fistula between 2003 and 2015) remains deeply inadequate in relation to the scale of the issue (in the same period only 35,000 women received social reintegration services). The 2016 UNGA Report on obstetric fistula notes that "tragically, at the current rate of surgeries performed, most women and girls with fistula will die without receiving treatment". As a failure to protect or promote women's human rights, this is an indictment.

Human Rights Watch notes that "fistula would rarely occur if women had access to family planning information and services to make informed choices about their sexual and reproductive lives and to emergency care when they needed it. Distance, cost, lack of autonomy, lack of transport, lack of information about potential complications during pregnancy and childbirth…and other barriers stand in the way". Those "other barriers" include attitudes to women and to medical support in childbirth, harmful traditional practices and the indifference of governments. All too often, the result is fistula.

As the UN Secretary-General and the UNFPA assert, obstetric fistula is the result of the denial and abuse of human rights. The provision of surgical solutions is only one aspect of what is needed to eradicate this demonstrably preventable condition.

Causative factors

Young, poorly educated women from rural areas, giving birth to their first child, make up the largest group of women with obstetric fistula, although women who have had several children are also at risk. Poverty is the main underlying cause of the prolonged, obstructed labour which results in obstetric fistula, due to its association with poor health and nutrition, stunted growth, limited access to health care, illiteracy and links to early marriage and early childbearing. Power imbalance, attitudes to women and gender-based discrimination inform the likelihood of experiencing obstetric fistula. For example, young women may be the last in the family to be fed and may have poor access to nutritious food, resulting in stunting and an under-developed pelvis, complicating childbirth and increasing their vulnerability to obstetric fistula; early age of first childbirth exacerbates this. Trauma, sexual abuse, coital injury, rape, infection and harmful traditional practices all increase vulnerability to fistula.

Thus, States which allow or tolerate early marriage, which do not protect women's rights, which do not provide equitable access to education or health services and/or which do not challenge patriarchal attitudes in domestic decision-making effectively are essentially perpetuating the conditions in which fistula can occur. Indeed, obstetric fistula demonstrates all too clearly the extent to which poverty is a feminised condition.

Similarly, without resolving the human rights abuses which comprise the underlying and root causes of obstetric fistula, and without engaging in necessary education, personal empowerment and health service provision, States effectively condemn a significant number of women in childbirth to the unnecessarily prolonged, obstructed labour that results in obstetric fistula. The experience of the fistula itself then magnifies their marginalisation and becomes a barrier to seeking surgical and other resolutions to their condition.

In many countries with high rates of obstetric fistula, professional, skilled birth attendants are present at less than 1 in 3 births, heightening the chances of developing fistula, though such assistance must be timely, with good access to emergency obstetric care, to be of preventative benefit. Well-grounded fear of abusive treatment, antipathy to Caesarean sections, lack of female medical personnel and other concerns often prevent women from seeking medical support in childbirth. Should they seek support, delay – to seek help, to reach a health facility, to receive care at the facility – all of which are exacerbated by multiple forms of marginalisation– may result in fistula, despite the women's best efforts.

There are often no family or community resources available to protect young women's sexual integrity or reproductive health. The greater decision-making power of male family members or local elders frequently prevents women from seeking assistance, even when childbirth is becoming protracted and problematic. The reproductive rights of women are often violated, and decisions regarding pregnancies are made by men and influenced by religious and cultural beliefs and myths (Lawani et al, 2015). For example, in some sub-Saharan African countries it is believed that making preparations for childbirth can result in misfortune, while in others there is a preference for the first child to be born at home. Some traditional practices, such as giving women water to drink as an aid to the expulsion of the baby, are counter-productive (a full bladder can increase the risk of fistula formation).

Consequences and effects

"Incontinent, reeking of urine and faeces, and suffering incontinence-related infections, they are barred from family homes, prohibited from cooking for others and touching shared utensils, and forced into isolation. Denied family support, their poverty and malnutrition may be aggravated, and they may be forced to depend…on begging, prostitution and comparably stigmatising employment" (Cook RJ et al, 2004).

The most apparent consequence of obstetric fistula is the constant leaking of urine, faeces and/or blood. Burn wounds from the acid content of the leakage, nerve damage causing mobility impairment and ulceration of the vaginal tract are some of the main effects. In an attempt to reduce the leakage, women often limit their intake of water and other fluids, thus increasing the smell and acid content, as well as causing damaging dehydration, ulceration and infections. Limiting food intake, for the same reason, causes anaemia and exacerbates malnutrition. Limb contractures can result from lying still in the same position in order to reduce leakage.

Incontinence in and of itself is stigmatising and is frequently viewed as polluting in many societies. It often results in being outcast and abandoned. In many cultures obstetric fistula is seen as a divine punishment for infidelity or other misbehaviour, or as a venereal disease, increasing the stigma ("when I went outside people would laugh at me, pointing"). Limb contractures and mobility impairment can add the stigma of visible disability to the toxic mix.

In communities with poor access to water, women with fistula are often unable to wash themselves and their clothes regularly. The effects of this, and the prohibitive cost of soap, especially in Islamic cultures, with their emphasis on ritual cleanliness, is to deepen the women's isolation and social unacceptability.

Being able to look good is an important element in self-esteem. Having to wear "ugly or old dresses" because of the risk of ruining good ones has a depressing effect on the women's view of their own worth. "Failure to keep clean and dress nicely robbed their happiness, and self-esteem, and they always envied other women who dress nicely and walk confidently. Women could not go to parties,

church or to mosque for prayers, visit friends and families nor attend funeral ceremonies that are culturally important and essential activities in maintaining social networks" (Mselle et al, 2015). This may include the denial of access to their other children.

Essentially, the discrimination and stigma associated with obstetric fistula prevent affected women from free, active and meaningful participation in, contribution to and enjoyment of civil, economic, social, cultural and political development, thus forming a barrier against their realisation of their human rights and the fundamental freedoms which are their due. Frequently ostracised even by their own families, they often live as outcasts, dependent on charity or menial work, cut off from gaining the information that could lead them to repair or unable to access it due to cost, location or belief.

The value in society of poor rural women is often derived solely from their status as wives and mothers. By disrupting this, by causing infertility and stillbirth and by so often resulting in divorce and abandonment, obstetric fistula threatens women's entire being – with disastrous consequences. Suicidal ideation is often reported (for example, "sometimes I planned to take some kind of medicine and become dead, just to get relief", quoted in Yenenesh, 2014). Remaining married is no guarantee of an actual marriage relationship.

Access to surgical repair is clearly essential for those who endure obstetric fistula, but even after successful surgery, some status-changing health issues, such as amenorrhea and mobility impairment, both deeply stigmatising in poor, rural communities, often remain. Without children women are often considered to be of low value and thus become the target of insults and poor treatment. Discrimination increases, condemning many of the younger women who make up the majority of those with fistula to further distance from the possibility of achieving status or rights. Outside marriage, women may have little or no social or economic security as they cannot fulfil expected and valued gender roles. Younger women, with no experience or marketable skills, are particularly vulnerable.

Not all medical interventions are successful. Estimates for post-operative stress or other incontinence range from 10% to 33%, due to weakened or damaged pelvic floor musculature. "Unsuccessful repairs left survivors worse off; they were seen as cursed and were alienated" (Khisa et al, 2012). Even when successfully treated, women, particularly in Asia, may be considered to be "socially polluted" and thus unable to regain their former status. Even successfully treated women are not always able to reintegrate fully into their communities, and the worry of recurrence often prevents women from returning to sexual activity. Residual pain and fatigue are among the elements that may prevent a full return to "normal living" and work, thus cutting women off from another major source of personal value and self-esteem.

Obstetric fistula disrupts women's sense of their own identity and self-worth. "You cannot even get close to someone to be comforted" (quoted in Roush, 2009). Girls and women with fistula often eat alone, sleep alone and pray alone (Bangser, 2006).

Obstetric fistula is thus associated with high rates of stigma and psychological morbidity. Over 85% of those with fistula are also mourning the death of a child, and this loss, often coupled with a later inability to conceive, frequently results in permanent loss of status. Consequently, recovering from obstetric fistula requires far more than surgical repair. Clinical depression is common. Psychological and social support is essential for re-establishing life in the community and rebuilding self-esteem. Yet, to date, such attention as has been paid to obstetric fistula has largely concentrated on surgical repair alone. Even after successful repair, the horrific experience of the fistula cannot be erased,

and “it is unknown to what extent re-integration parallels pre-fistula status” (Byamugisha et al, 2015). What is clear, however, is that without support networks in the post-surgery period, quality of life remains very poor.

When interviewed, communities may deny the blatant or subtle stigma that persists even after successful repair, especially when the women cannot have more children, or when subsequent pregnancies result in stillbirth. Family support reduces over time, unless there are surviving children. There appears to be no available literature on the risk of domestic violence, murder and honour killing resulting from obstetric fistula. Yet, with improved knowledge, awareness and services, community and family mistreatment diminishes and there is less divorce…community attitudes are crucial factors.

Service provision

At present, efforts to eliminate obstetric fistula tend to concentrate on two courses of action: preventing the condition from occurring, through increasing access to skilled professional birth attendants, and surgical repair of fistulas which do occur.

Strategies to increase access to professional birth attendants, such as abolishing user fees in countries such as Kenya and Sierra Leone, tend to be framed in the context of preventing neonatal deaths. The WHO’s Every Woman Every Child Global Strategy for Women’s, Children’s and Adolescents’ Health (2016-2030), which takes a life-course approach to attaining the highest standards of health and wellbeing, mentions fistula only once, and then solely in terms of early detection.

In many countries, home births are still the norm. For example, according to the Tanzania Demographic and Health Survey, 2010, only half of Tanzanian women give birth in a health facility and, of these, only 50% receive skilled birth care. The dispensaries and health centres, where women go to give birth, often have no capacity to handle obstructed labour. They may have no transport to move women to a hospital with more facilities, if needed. In many places, low awareness results in the threat of obstetric fistula not being considered as a surgical emergency at all.

In communities in which hospitals are seen as places of last resort, to die in, women will not attend to give birth. In any case, giving birth in a health setting is no guarantee of quality service or avoiding fistula. The case of Snehalata Singh v The State of UP and Ors (India), filed in 2009 and still unresolved, offers an example of the way in which the public health systems all too often mistreat low-income pregnant women. This case alleges that neglect, and poor quality of care, resulted in an entirely preventable obstetric fistula which, though eventually diagnosed and repaired by an NGO, has had lasting physical, psychosocial and economic effects. The case is seen to violate Indian Constitutional protections to the right to life, the right to health and dignity, to equality and to non-discrimination, among others.

The case demonstrates that birth in hospital, often cited as a primary factor in preventing obstetric fistula, is, on its own, insufficient, or even potentially harmful. Staff must be trained and aware; dignity must be at the centre of the approach; fees must be within the reach of the poorest, or eliminated altogether. Woman-centred human-rights-based policy must be matched by practice in a coherent system which takes the rights of women seriously. Many complain of the rough and undignified way that they are treated by the staff (“They talk very badly. They just toss you from one person to another. They don’t even care. I could not go back there”). Credible grievance systems are rare and, even when they can, women are often afraid to complain for fear of retaliation. Health

service constraints, such as lack of resources, cannot be used as an excuse for mistreatment or the denial of rights.

While concentration on skilled birth attendance is clearly part of the solution, the effect on the rate of postpartum morbidities, such as obstetric fistula, is treated as almost incidental. Without naming the condition and its causes clearly, it is possible for obstetric fistula to remain in the shadows. Thus, as called for in GA resolution 69/148, obstetric fistula should be a nationally notifiable condition, thus triggering immediate reporting, tracking and follow-up, although clearly many health settings would find this challenging. Enhanced data collection, as recommended by the UNGA, is essential, but global databases, such as the WHO's DHIS 2, though of huge benefit, do not, of themselves, create change. Data collection must be undertaken sensitively: participatory research needs to consider whose perceptions of stigmatising conditions frame public understanding of obstetric fistula.

As previously discussed (page 2), efforts to date on the part of the UN, governments and NGOs to provide surgical repair services for women with obstetric fistula have made little headway. The 2016 UNGA Report on obstetric fistula
asserts that "addressing the unmet need for fistula surgical repair should be a high priority of the sustainable development agenda", but this aim is not binding or compulsory.

Cook et al (2004) are not alone in asserting that "time spent untreated may cause women to suffer irreversible losses". Even the three months minimum advised waiting time between the occurrence of fistula and its repair can be a torment, whereas there are many women who have endured the condition for up to 40 years, remaining "invisible" due to their marginalisation.

"Camps" and other centres dedicated to fistula repair do sterling surgical work, but are often donor-driven. While recognising the need for specialisation, it is important that fistula repair services are located in ordinary hospitals, and not kept separate, which can serve to reinforce stigma. Access to hospital social workers and others can also help in reintegration. "Camps" and other special initiatives are unable either to follow up clients or to do prevention work, so the ongoing psychological and mental health effects of the experience of fistula remain unresolved.

According to various studies, reconstruction is successful in 65-95% of cases, depending on size and location of fistula, length of time since the injury occurred, and other variables. However, many women who experience the condition lack the resources or, crucially, the autonomy, to access appropriate information, make informed decisions or to seek surgery. The follow-up of women who experience fistula remains a major gap in the continuum of care, as is any major effort to address the needs of those women whose fistula is inoperable or irremediable. Their psychosocial needs, along with those of women whose fistula is responsive to surgery, remain largely ignored, except through small-scale interventions undertaken by NGOs. Much research on fistula repair tends to focus on clinical outcomes alone, without considering the broader goal of successful reintegration into family and community, whether or not surgery is successful.

The WHO's advice to integrate fistula repair into safe motherhood programmes is excellent. But these measures are insufficient. Addressing the human rights issues which lead to the experience of fistula is necessary for eradication. Access to quality health information, and reproductive and maternal healthcare, are essential, but so are women's empowerment, tackling gender-based exclusion and discrimination, providing access for women to education, training and information, ending early marriage and a host of other gender-related issues. The general principles laid out in A/HRC/21/22 (Technical guidance on the application of a human rights-based approach to the

implementation of policies and programmes to reduce preventable maternal morbidity and mortality, 2012) spell out the approach to be taken. Will and implementation are the only real arbiters of improvement.

Men

The role of men in ending obstetric fistula is at present only sketchily considered in most of the literature and projects concerned with the topic. In many affected communities, men's views and beliefs trump those of women. As gatekeepers and decision-makers they can and do both facilitate and impede access to appropriate childbirth-related services. Even in the most benign relationship, a man may be unaware of when to judge that a childbirth emergency has occurred. In many circumstances – for example, in the reintegration of women with fistula who have been excluded from the community - men's participation may well be a necessary pre-requisite for women's empowerment.

Raising awareness among men and community elders, examining social norms and gender issues, engaging men fully in the bid to eliminate the condition and to enable women to control their own lives and futures, and ensuring that men dismantle the barriers they operate which deny women the fulfilment of their human rights are aspects of the human rights-based approach to the elimination of obstetric fistula which have so far apparently received scant attention. The people-centred approach to development, necessary as a pre-requisite to ending obstetric fistula, will work only if it involves everyone, men as well as women.

UNGA

Based on UNGA document A/71/306 (Intensifying efforts to end obstetric fistula, Report of Secretary General, reissued 31 August 2016), UNGA Resolution A/C.3/71/L.16/Rev.1: 16 Nov 2016 is the sixth such Resolution on obstetric fistula in the last ten years. It stresses the context of women's development and gender equality and international human rights instruments. Importantly, it recognises the links between poverty, malnutrition, inadequate or inaccessible health services, early marriage, early childbearing, gender-based violence and gender inequality as the root causes of obstetric fistula, with poverty as the main risk factor, thus clearly placing the condition in a human rights context. It names the social issues that underpin the condition, including the continued low status of women in many countries and communities.

The Resolution notes the necessity to adopt a human rights-based approach to eliminating the condition, using the principles of accountability, participation, transparency, empowerment, sustainability, non-discrimination and international cooperation, among others. It also details the effects of the neglect and stigmatisation of women who have obstetric fistula or who are recovering from it, noting the deleterious effects on their mental health, including depression and suicidal ideation, as well as being driven deeper into the poverty and marginalisation (and distance from the fulfilment of their human rights) which were causal factors of their contracting the condition in the first place.

In calling for a wide range of measures, from adequate nutrition to improved information services, from culturally accessible healthcare to quality education for women and to the enforcement of laws concerned with the age of consent, the Resolution enumerates the many dimensions of the human rights-based approach to eradicating obstetric fistula. It calls upon States and UN agencies to work to end obstetric fistula within a generation by redoubling their efforts on a multiplicity of fronts.

What the Resolution fails to do is to establish an accountable international system for tackling obstetric fistula, leaving it to each Ministry of Health to establish or strengthen its national task

force. In dealing with the situation of women who have undergone treatment, or whose condition is inoperable or irremediable, the Resolution falls back on civil society organisations and gender empowerment programmes to give women the tools to overcome their own exclusion. The UNGA report, on which the Resolution is based, details innovative approaches to raising awareness and increasing access to treatment, often using mobile telephony in inspiring new ways. It is notable, however, that these are either CSR or charitable initiatives, rather than being led by governments. It is also clear that those governments which have made sterling efforts, such as Bangladesh, have only been able to provide services to relatively small numbers of women.

The approach taken by the non-binding UNGA Resolution may well be practical in the circumstances as currently configured, but it cannot tackle systemic human rights abuses, nor can it establish the society-wide initiatives that can transform the context in obstetric fistula continues to manifest, or end the marginalisation of affected women, whether or not they experience successful surgical repair.

The report on which the Resolution is based offers recommendations to intensify global, regional and national level efforts to end obstetric fistula, using a human rights-based approach, and places these efforts in the context of the Sustainable Development Goals (SDGs). It emphasises the need to provide access to education and health care for all, especially the poorest and most vulnerable girls and women and to tackle the economic and sociocultural factors that negatively affect women, including through educating men and boys and encouraging community involvement. It recognises the necessity to scale up country capacity to provide access to comprehensive emergency obstetric care, treat fistula cases and address underlying health, socioeconomic, cultural and human rights determinants.

Essentially, however, both the document and the Resolution offer no more than encouragement. They point the way, rather than mandating game-changing imperatives. They reiterate the importance of taking a human rights-based approach to eliminating preventable conditions such as obstetric fistula, but stop short of implanting it. The requirement to take action must be strengthened if large-scale change (such as eliminating obstetric fistula in a generation) is to happen.

Obstetric fistula, disability and human rights

There are compelling reasons to consider obstetric fistula as an impairment which results in disability, thus bringing women who experience it under the ambit of the UN Convention on the Rights of Persons with Disabilities (UNCRPD). The UNCRPD recognises that disability is the disadvantage that results from the interaction between persons with impairments and attitudinal and environmental barriers, which then hinders their full and effective participation in society on an equal basis with others.

In the case of women with obstetric fistula, their impairments (including *inter alia* bladder and bowel incontinence, mobility impairments, psychosocial impairments related to rejection, stigma and discrimination) are the result of barriers in society (for example, attitudes, lack of affordable maternity care within easy reach of where they live, lack of education or information in appropriate formats) and are exacerbated by interaction with more barriers (for example, lack of medical and psychosocial services, lack of information, community attitudes, often resulting in divorce and/or lack of access to children, and much more). All too often, the outcome is banishment from community life, poverty, malnutrition, unemployment, denial of access to public services, vulnerability to violence and abuse…all the documented consequences of obstetric fistula in the 21st century.

These experiences bring women with obstetric fistula into the company of millions of other people around the world who are excluded from everyday life in their communities, from the benefits of development and the fulfilment of even the most basic of their human rights (such as shelter and human relationships) because of disability. The UNCRPD defines discrimination on the grounds of disability as having "the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or other field".

Specific Articles of the UNCRPD which apply to women with obstetric fistula include Article 6 (on the rights of women and girls with disabilities, recognising the multiple layers of discrimination that they may endure), Article 25 (on the right to the enjoyment of the highest attainable standard of health, without discrimination on the basis of disability, including the right to services which are designed to minimise and prevent the development of further impairments) and Article 26 (on habilitation and rehabilitation), among others.

These denials of human rights are systemic. Raising the awareness of individuals and families is essential but, to be effective, States must tackle overall social attitudes and priorities. Offering surgical repair to individual affected women is vital but, to be effective, States must have overall health policies and practices that reduce the incidence of obstetric fistula to zero. Pilot projects tackling the psychosocial damage resulting from the experience of obstetric fistula and the community's response to it can transform the lives of individual women but, to be effective, ways must be found to deliver support to affected women in every community as a matter of rights.

At the heart of the issue lies the necessity to believe that all lives matter, and that, in the spirit of the SDGs, assuring the fulfilment of the human rights of younger, poorer, less educated, rural women with impairments will ensure the fulfilment of human rights for everyone.

A human rights approach to obstetric fistula

"The persistence of fistula is a result of human rights denied and a reflection of human rights abuse. It reflects chronic health inequities and health-care system constraints, as well as wider challenges, such as gender and socioeconomic inequality, child marriage and early childbearing, all of which can undermine the lives of women and girls and interfere with their enjoyment of their basic human rights" (Babatunde Osotimehin, Executive Director, UNFPA).

According to the Campaign to End Fistula, coordinated by UNFPA, "a woman with obstetric fistula spends each day surviving, not 'living'." In such circumstances, human rights are impossible dreams. As a postpartum disability, obstetric fistula is a debilitating condition which, in the words of Center for Reproductive Rights and the Human Rights Law Network, "implicates [women's] rights to life, health, equality and non-discrimination, and to be free from cruel, inhuman and degrading treatment".

As previously discussed, until recently obstetric fistula received attention mainly as a surgical issue. Recent UN reports and resolutions place it in the realm of human rights, but continue to stress repair as the most urgent requirement. However, the broader human rights violations which impede women's wellbeing and opportunities inform the conditions in which obstetric fistula continues to occur. Essentially, the failure of States to prioritise the eradication of obstetric fistula is caused by and adds up to a violation of women's human rights. Recognising a condition as a human rights violation emphasises its gravity, rather than viewing it as a private tragedy. Programmes of change depend for their existence on naming issues in international treaties and fora. Leadership on eradication needs therefore to come from the human rights structures of the UN.

For obstetric fistula to be eradicated it is essential to address the legal and institutional context in which violations of sexual and reproductive health arise, as well as the gender inequalities and other social barriers which prevent women and girls from accessing nutrition, information, education and health services. Measurable and observable targets for the eradication of obstetric fistula, with clear accountability for their achievement, are essential. States must be held accountable for their actions and inactions – progressive implementation should still show incremental results. National plans must be comprehensive and observably monitored, to include a requirement for regular reporting to the international community. There is a need to develop governance structures that bring the voices of marginalised people into public policy settings, and those of women and girls into decision-making processes.

States must be held to account for their obligations under existing treaties to women at risk of developing obstetric fistula, or who already endure the condition. These treaties include, *inter alia*, CEDAW (for example, Article 16, on the elimination of discrimination against women in all matters related to marriage), the International Covenant on Civil and Political Rights (for example, Article (6)1 right to life – when ostracism due to fistula results in women suffering malnutrition or suicidal ideation and Article 9(1) – security of the person), and the UNCRPD (see page 10). Eliminating early marriage also needs far more attention: for example, in some parts of Ethiopia, despite the law, half of all girls marry before the age of 15. The low political priority given to healthcare, especially of people living in poverty, must be challenged and overcome.

Despite recent progress in developing human rights standards in the context of maternal mortality and morbidity generally (in particular, UNGA A/HRC/21/22), international human rights standards on mistreatment during facility-based childbirth are still in an early stage of development. Such work as has been undertaken focuses largely on forced sterilisation and lack of access to emergency obstetric care. The extensive range of mistreatment to which women are known to be subject during childbirth, however, is a potent disincentive for women to attend health facilities in the low- and middle-income countries which have high rates of obstetric fistula. Furthermore, mistreatment in healthcare facilities, especially neglect and delay or denial of services on the basis (among other things) of inability to pay or membership of marginalised groups can itself result in obstetric fistula (see page 7). For many poorer, younger, less educated women with or at risk of obstetric fistula, these are abuses of power. Where they occur there are clear breaches of human rights, as well as ethical, standards.

From a human rights perspective, while equitable and timely access to treatment is essential, the aspects of prevention, tackling discrimination and stigma, and the reintegration of those who endure the condition are equally vital, urgent and important. The general concentration of obstetric fistula among younger, poorer and marginalised women cannot be allowed to compromise States' obligations to eliminate the condition and to ensure the achievement of the human rights of those who endure it. As duty-bearers, States need to recognise their obligations to this ostracised and disempowered population, and to take responsibility for eliminating the condition with alacrity.

According to the 2016 UNGA report on obstetric fistula, there is a "tremendous unmet need for fistula treatment". Work to date on reducing child mortality and improving maternal health, although also aiming to end the early marriage that is a noticeable factor in many incidences of obstetric fistula, skirted the issue, rather than shining a clear light on the human rights aspects of obstetric fistula. Sustainable medical solutions require strengthened health systems, well-trained and well-equipped health professionals, access to and supply of essential medicines and equipment, and equitable access to high-quality reproductive health services, affordable by the poorest families.

Without these services, any woman or girl who experiences problems during childbirth and does not receive appropriate and timely medical care will continue to be risk of developing obstetric fistula, and this situation will continue in and of itself to be a clear violation of her human rights. Many women are not aware of those services which are available, or cannot afford them, or cannot access them due to other barriers, such as transport costs.

Women enduring obstetric fistula deserve to be seen as resilient survivors, with agency. It is necessary to stop treating them as passive victims, and instead to recognise them as key actors in their own development and future. Women with past or present experience of obstetric fistula should be actively and meaningfully involved in the design, delivery and evaluation of measures and actions taken to eradicate the condition and to transform for the better the lives of those who endure it. For example, in recent years One by One, a Kenyan NGO, reached over 125,000 people in 15 months using a network of fistula survivors and community volunteers. Crucially, this involved reintegration support as well as community education and identifying women for surgery.

Women with obstetric fistula are rights-holders, not just recipients of protection, rehabilitation or wellbeing. Paternalistic measures and charity are inadequate to tackle decisively the causes and outcomes of obstetric fistula. It is States, not charities, which should take responsibility and be held to account for support and remedial services for women with obstetric fistula. Human rights standards and principles must be used to monitor and evaluate States' and UN actions and outcomes in relation to obstetric fistula.

In line with the SR's own expressed views (2014), VIVAT International believes that the Post-2015 Development Agenda should have a transformative impact on the lives of women and girls. It is essential to respect, protect and guarantee rights, starting from the current position, in which women at risk of or with experience of fistula are alienated from the systems of power or influence that keep them in their vulnerable state. Enhanced accountability and determination, based on human rights principles and recognition of the equal value of women and men, are the prerequisites of the action necessary for ensuring that the present generation of women with obstetric fistula is the last to endure its indignities.

A way forward

The continued incidence of this entirely avoidable condition, which affects an estimated two million women, mainly in Africa and Asia, condemns women, their families and communities to living in literal "pain and shame". It serves to exclude affected women from achieving even the most basic of their rights, not just in relation to physical health, but also with regard to shelter, family relationships and other determinants of good mental health.

In the light of the recent discussion at the UNGA on the situation of women who have obstetric fistula, and the proactive initiatives taken by UN bodies to combat the issue, this paper urges the UN Special Rapporteur to redouble efforts to eliminate this preventable human rights abuse, and to enable women who currently endure this devastating condition to achieve their long-denied full human rights. Despite UNFPA action since 2003 and UNGA resolutions since 2007, impact on the ground remains inconsistent. UNGA A/71/306 (2016) calls obstetric fistula "a severe maternal morbidity and a stark example of inequity". As such it deserves a far more robust approach, going beyond detection and surgical repair, and based squarely on ending the human rights violations which both cause the condition and are the result of experiencing it.

Medical services for women with fistula, at present patchy and inconsistent, are essential, but on their own are insufficient to dismantle the barriers preventing affected women, and those at risk of

developing the condition, from achieving their full human rights. VIVAT International urges the UN Special Rapporteur to use all available means to make States accountable for the eradication of the condition, for the provision of equitable repair and rehabilitation services as matter of rights, rather than charity, and for the elimination of harmful practices, discrimination, health inequalities and stigma associated with the incidence of obstetric fistula.

Human rights standards related to obstetric fistula need robust attention. Authoritative interpretations from treaty-making bodies, Special Rapporteurs, the Human Rights Council and other international bodies, all expressly naming obstetric fistula as both resulting from and leading to violations of human rights, are needed in order to create constructive accountability and to prevent future violations.

As well as being a priority for States in relation to their obligations under international treaties, the eradication of obstetric fistula should be a named element of their commitment to the achievement of the Sustainable Development Goals (SDGs). The "vast potential for transformative change" in the lives of women with obstetric fistula represented by the SDGs must be unlocked. Ways must be found to get more urgency for concerted action at State level into the UN system, so that States become compelled to tackle the issue in a more determined manner, whether as donors, funders, co-operators or as countries in which the problem still exists.

An Interactive Dialogue on the topic at the Human Rights Council in Geneva, exploring best practice in the resolution of the problem at local, regional, national and international level, may be one way of expediting concerted effort and introducing more accountability and transparency into the system. The emphasis on country leadership and States' obligations under human rights treaties must be strengthened, with clear responsibility for monitoring national data and progress being allocated. Urgency needs to enter the system. Admirable activities, for example, in some West African countries in 2015, to reduce the rate of obstetric fistula and accelerate the rate of repair and rehabilitation, reach tens or hundreds of women, rather than the thousands in need.

UNFPA's leadership on the issue of eliminating obstetric fistula is now under threat due to decreasing funding. Reports and resolutions presented at UNGA in 2016 are significant, relevant and very important, but non-binding. The world's approach to eliminating obstetric fistula remains fragmented. Unless and until the issue of obstetric fistula is streamlined in the UN system, with all relevant agencies and programmes seeing it as part of their work – in terms of women's human rights and development, community resources, health status and outcomes, children's rights, and much more – the issue will continue to be marginal. Yet, beyond the indignities and pain of the condition itself, obstetric fistula stands for a range of human and health inequities which highlight the continued and complex marginalisation of people who embody multiple layers of exclusion and whose voices are almost never heard. Tackling obstetric fistula systemically will offer the demonstration of an approach that can be applied to other pressing multinational and multi-factoral issues.

Robust action has the potential to end fistula within a generation. The UNGA report calls the continued occurrence of obstetric fistula "a human rights violation" because "in the twenty-first century, the poorest, most vulnerable women and girls suffer needlessly from this devastating condition, which has been virtually eliminated in much of the world", and the world appears to agree. What now needs to be done is to tackle it systematically, from a human rights standpoint. This will require significantly intensified political commitment, at all levels from local to global, a practical and monitored global action plan, more funding and real accountability, as part of the

promotion and protection of the human rights of some of the world's most at-risk women. With determined leadership, it can be done.

Appendix

About VIVAT International

We are a coalition of 13 religious congregations and societies along with our co-workers and partners under the umbrella of VIVAT International to promote, protect, and respect life in all its forms and its fullness for all people and creation, working to restore the dignity of each human person, through a human rights based approach. "Together for life, dignity and rights" speaks for our collective vision, mission, goals and initiatives.

Sharing a vision of the world and of every human being as created in goodness and dignity, and believing, defending and proactively supporting the equality in rights and in dignity of all individuals, peoples and cultures, VIVAT's presence at the UN envisages attaining a world of equality, justice, reconciliation, peace and care of the environment.

VIVAT engages in a two-fold mission of working at the grass-roots as well as doing advocacy work at the United Nations. VIVAT is accredited to the UN through ECOSOC.

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