Evidence
Review Team | 5

Stigma & Discrimination

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Introduction

The ERT 5 working group (ERT5WG) was charged with identifying and reviewing interventions that seek to reduce stigma and discrimination in order to promote child health in low and middle income countries, with the aim of identifying characteristics of interventions that are effective and produce population level impact. The child health program areas of interest are those associated with the major causes of child morbidity and mortality – nutrition, HIV (prevention and treatment), malaria, acute respiratory illness, diarrheal disease, and immunization.

Child well being is interwoven with their environmental experiences and their opportunities to meet their potential. This review will explore the concepts of stigma and discrimination, and how they affect, impede or divert child health and development outcomes and pathways. In order to summarise the literature it is important to recognize the multitude of concepts held under the ideas of stigma and discrimination, and to broaden the theme so as to include a linked concepts of marginalization and social exclusion.

Stigma and discrimination are clearly factors that can significantly affect child health. Stigma has been documented in association with a wide range of conditions such as leprosy (van Brakel et al, 2012), epilepsy (Viteva 2013), tuberculosis (Courtwright & Turner 2010), disability (Ali et al, 2012) and all manner of mental health diagnoses (O'Driscoll et al, 2012, Kleinman 1995). Research on stigma associated with these conditions has demonstrated that the social processes of stigmatization and discrimination can have complex and often devastating effects on the health and welfare of individuals, families and whole communities. While there is limited published research on stigmatization of children (less than age 5), the health and human development of children is profoundly affected by the environment in which they live, learn and grow (Wilkinson & Marmot 2003). That is, stigmatization and discrimination against a child's family or community should be expected to affect his or her health and life chances.

Research concerning children affected by HIV has shown that HIV-related stigma amplifies the negative effects of loss and economic deprivation resulting from parental illness, disability and death (Foster & Williamson, 2000). For example, Cluver and colleagues (Cluver et al, 2013, Clover et al 2007, Cluver et al 2010, Cluver 2011) have shown clearly that children affected by HIV – for example, those caring

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for a sick adult with HIV infection or those orphaned by AIDS - compared to those orphaned by other means (Cluver 2008), report high levels of mental health burden, exacerbated considerably by experiences of stigma.

More broadly, it is well established that stigma, discrimination and social exclusion impede both provision and uptake of health information and services by young people and adults in contexts ranging from housing and employment to health care (e.g., Turan et al 2013, Pulerwitz et al, 2010).

It is clear that stigma is an important factor and that interventions which can reduce or remove stigma or that might reverse its effects could actively contribute to health behavior that enhances child health and development outcomes. The purpose of this review was to try to identify promising interventions that might have this effect.

Focus of the Review

The ability of social groups to assign stigma (a discrediting mark or negative judgment) to people, attributes and/or behaviors and to sanction people who are so stigmatized is a fundamental mechanism of informal social control (Goffman 1963, Giddens 1984). Stigmas are socially defined meanings, and stigmatization is a social process, whereby the meanings are applied to certain people or behaviors. Stigma persists both because they are reinforced and replicated in and by a range of interlocking social norms and institutions – including norms which legitimate *discrimination (differential treatment)* against stigmatized individuals or groups. Stigma also persists because members of a social group have internalized their group's values and norms. Thus, just as we judge and discriminate against others according to our shared attitudes and norms, as members of a group we tend to feel shame and regret if a stigma is applied to ourselves, and we seek to eschew and/or deny behaviors and associations that could earn us the stigmatizing mark. Furthermore, organizational and national policies reflect social values and norms. They may replicate and reinforce social stigma actively (e.g. through criminalization, or disqualification for services), or passively (e.g. through neglect and lack of investment), according to structural factors ranging from economic and geographic distinctions to differences in ethnicity, occupation, or sexual orientation. Thus stigma and discrimination are profoundly political (Parker and Aggleton, 2002).

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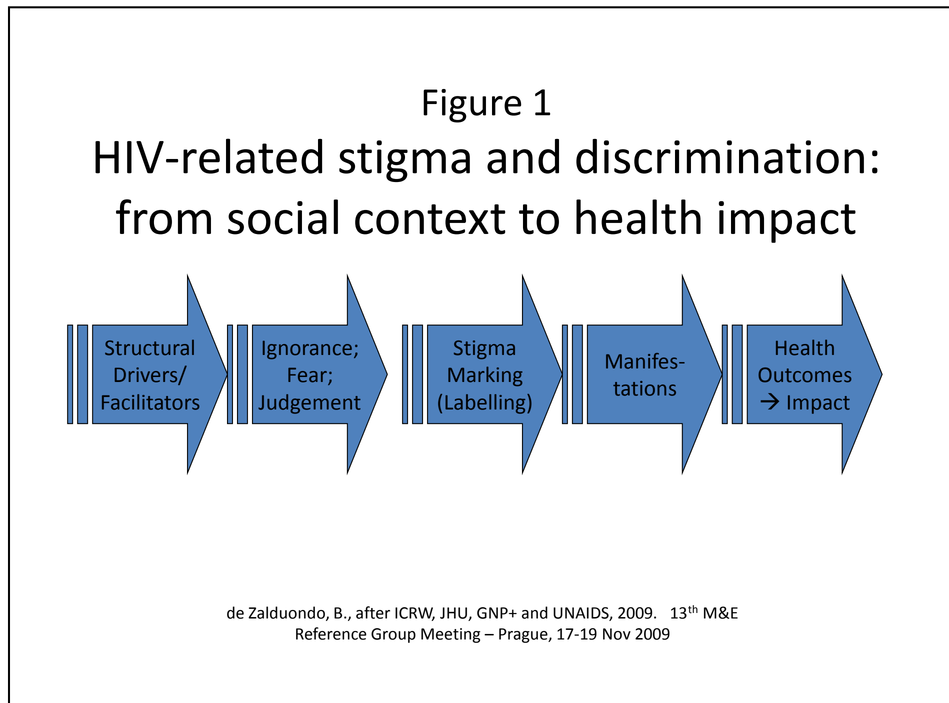
Theorists have clarified the complex processes that connect learned attitudes and feelings, group norms, and discriminatory practices, policies and laws (see Figure 1, next page).



Most theorists distinguish *felt stigma*, the personal experience of being stigmatized, from *enacted stigma*, the discriminatory acts and behaviors that are experienced (e.g., Mahajan et al. 2008, see Figure 2 next page). They further distinguish *individual discrimination*, acts taking place between two or more people, from *structural discrimination*, accumulated institutional practices that disadvantage stigmatized groups and that can work in the absence of individual prejudice and discrimination. This distinction is important because communications interventions may be more directly and immediately effective in affecting individual behavior and attitudes or social norms, whereas political analysis, organizational change management and strategic advocacy are required to shift policies and institutionalized practices (e.g. UNAIDS 2007).

Given the breadth of the stigma construct, and its complex social roots, a variety of strategies have been tried and evaluated to combat HIV-related stigma and

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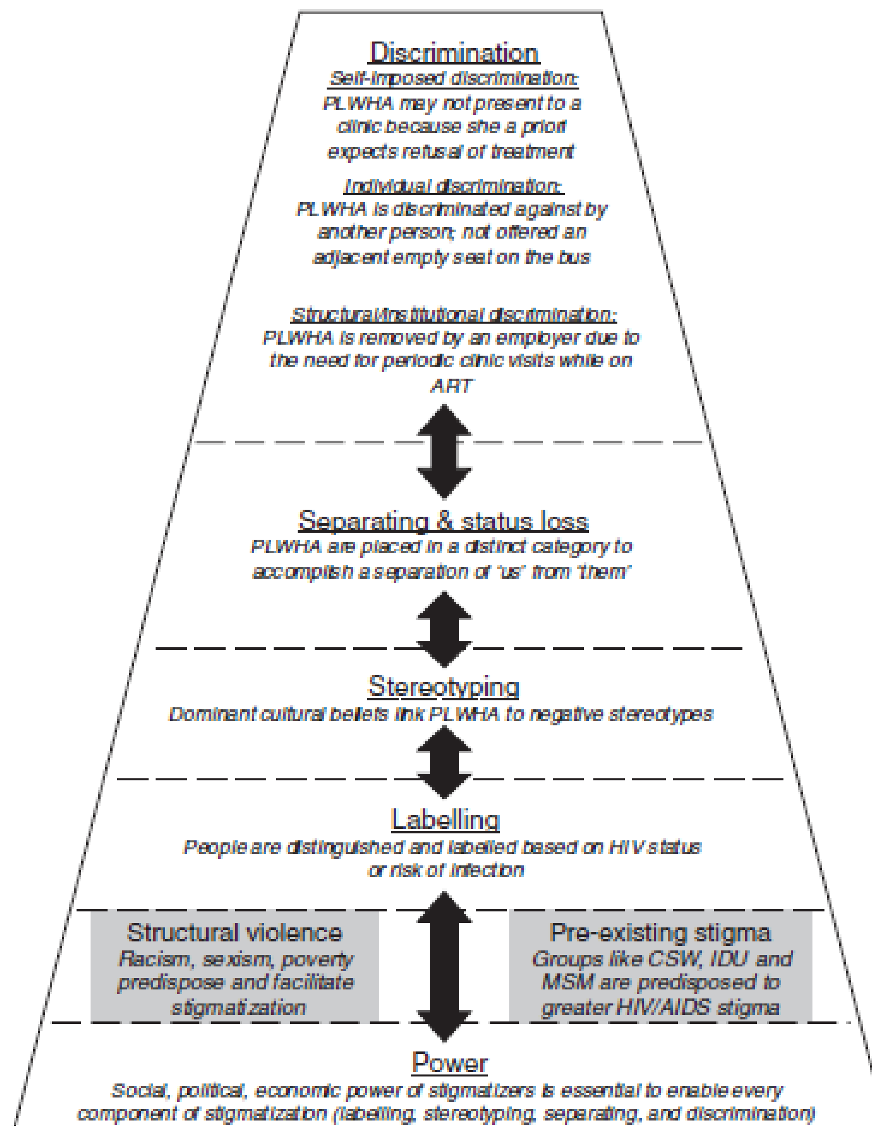
discrimination. Brown et al. (2003) identified four kinds of intervention approaches 1) information-based strategies; 2) skills building elements; 3) counseling elements, including self-help groups; and 4) interaction and collaboration with affected people, including testimonies. These four elements address the intermediate processes – the ignorance, fear and social judgment, stigma marking, and the manifestations of stigma. In addition, policy interventions, such as promotion of laws and policies that prohibit discrimination based on sexual orientation, or HIV status, have been implemented to address structural causes of HIV-related stigma and discrimination (e.g. UNAIDS 2012).

Figure 2

Illustrative Conceptual Framework for HIV/AIDS related stigma



For the purposes of this review, it is helpful to consider the relationship between marginalized populations, disease, prevention and treatment. Populations experience discrimination as a result of attributes such as color, caste, ethnicity/language, religion, sexual preferences or practices, drug use, poverty etc. Marginalized populations are more vulnerable to many diseases as a result of factors such as low access to education and employment, living in "riskier" places, having lower access to preventive and curative measures (Flaskerud et al, 2008, Gill et al, 2013, Castro & farmer 2005), fewer skills and knowledge, and lower self-efficacy. Some diseases and health conditions to which marginalized populations are more vulnerable are stigmatized by virtue of their association with stigmatizing attributes, such as poverty, or involvement in a stigmatized occupation, such as sex work. - HIV is the sole example among the conditions related to child health that ERT5WG was asked to consider; TB would be another, although it is not a major direct threat to child health. As for other diseases and conditions that the group was asked to consider – malnutrition, diarrheal disease, ARI, malaria – though more prevalent among marginalized groups, the condition per se does not evoke shame or elicit discrimination. It is not surprising that no interventions directly addressing stigma or discrimination were identified for these health conditions. It is important to point out that interventions addressing the intermediate factors – access, self-efficacy, knowledge and skills mitigate the effect of marginalization on prevention and treatment. The ERT1-3 reviews cover interventions related to intermediate factors for malaria, diarrheal disease, ARI, immunization and nutrition.

For HIV-related interventions, this review considered both those directed at the stigma and discrimination (direct) and at intermediate factors such as skills, knowledge and self-efficacy (indirect). Reviews were not limited to interventions addressing children; as explained above, stigmatization of parents can have a profound effect on child health and child outcomes may be affected by interventions focused on parents or the community.

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Other issues regarding interventions that should be considered, but that were not addressed in the research reviewed, are:

a) Interventions that might inadvertently stigmatize. One example is interventions that focus on children orphaned by parental death from HIV; while the intention is to provide for orphaned children, the intervention may lead to stigmatization of the orphans, resulting in alienation and negative reactions.
b) Interventions that do not address stigma or discrimination either directly or indirectly but that may reduce stigma. Historically, widespread recognition of effective curative treatment (e.g., of leprosy, tuberculosis; and HIV in some areas) has reduced stigma associated with the disease.

Stigma is a complex phenomenon and is not a stand-alone issue. Stigma may be measured as an experience and also an outcome measure. It thus becomes difficult to navigate the literature and generate clarity of understanding of the extent and range of stigma, the effects on child development and outcome, and factors that could change stigma experience and stigma behaviors.

Method & Challenges

The initial search of the literature identified 22 possibly relevant papers. An extended search, using an expanded list of terms referring to marginalized populations identified a possible further 15 papers but closer examination showed that most either were not interventions or did not address stigma/discrimination or intermediate factors. A further challenge was that most of these papers provided very little information about the interventions. Finally, when interventions are complex (e.g., Khumalo-Sakutukwa et al. 2008), it is difficult to dissect out the discrete elements that might have affected stigma; in addition, it must be remembered that the effect might not be replicable apart from the full intervention.

An additional challenge to assessing effectiveness of interventions is posed by the difficulty of measuring outcomes. Stigma is complex to measure, with a number of scales and measures utilised in the literature. An extensive range of tools and models now exist for identifying and measuring HIV-related stigma in specific communities and institutions such as health-care facilities and for designing, evaluating and reporting on interventions to combat three interlocking sources of stigma lack of awareness of stigma's hurtful effects, misinformation about HIV transmission, and social judgment about people and behaviors associated with HIV. These models range from the PLHIV

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stigma index, in which PLHIV lead both the implementation and analysis of research on stigma in their communities to regional mass media campaigns against homophobia (PAHO citations). Currently stigma is measured using a variety of complex scales (e.g., Boyes et al. 2013, Tsai et al. 2013).

Review Findings

HIV Related Stigma in the Context of PMTCT

In the context of HIV, stigma, discrimination, and inequality contribute to negative health outcomes for children and their parents, and disproportionally affect poor or marginalized groups (Castro & Farmer 2005). Limited access to and uptake of services to prevent mother-to-child transmission of HIV (PMTCT) due to the fear of or the experience of stigma and discrimination is a prominent example of how child survival can be influenced by stigma.

Preventing mother-to-child transmission requires the successful uptake or adherence to several constituent steps, often referred to as the 'PMTCT cascade'. These steps include: early HIV diagnosis during pregnancy, women's acceptance of CD4 testing, prompt uptake of either short-term antiretroviral (ARV) prophylaxis or life-long antiretroviral treatment (ART) depending on CD4 cell count, high adherence to maternal and infant drug regimens, adherence to infant feeding guidelines and early infant diagnosis (WHO, 2012). In order for women and children to receive the most benefit from PMTCT services, consistent engagement in maternal care and reliable medication adherence are required. Yet PMTCT programs globally are experiencing challenges in achieving the levels of engagement and adherence needed (Buyse et al. 2006, Coetzee et al. 2009). Given that treatment of women with CD4+ cell counts of <350mcl will prevent at least 75% of infant transmissions, as well as most maternal deaths (Kuhn et al. 2012), medication adherence among HIV positive women during and following pregnancy is critical.

A growing body of literature indicates that each of the linked processes in the PMTCT cascade may be negatively influenced by the stigma that HIV-positive pregnant women face in the health care setting, as well as in their families and communities. Recent research indicates that HIV stigma and discrimination affect pregnant women's decisions to enroll in PMTCT (Ekouevi et al. 2004; Painter et al. 2005) and impedes their retention and adherence in these services (Bwirire et al. 2008, Awiti et al. 2011, Mepham et al.

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2011, Duff et al. 2010, Turan et al. 2011). It has been estimated that more than half of vertical transmissions in some settings can be attributed to the cumulative effect of stigma at each point in the PMTCT cascade of services (Watts et al. 2011).

To date, no studies have evaluated stigma-reduction interventions for pregnant women living with HIV or the direct impact of HIV-related stigma on the uptake of PMTCT services. However, a growing body of literature suggests that interventions to reduce negative attitudes towards PLHIV among community members and anticipated and internalized stigma among HIV-infected pregnant women, may improve HIV care outcomes for this population. Evidence shows that interventions using a combination of sensitization and participatory activities can reduce stigma in health care and community settings (Apinundecha et al. 2007, Nyblade et al. 2008, Oanh et al. 2008), but few PMTCT programs have systematically applied these strategies and no rigorous research has been conducted to measure the impact of these program enhancements on key PMTCT outcomes, including infant sero-conversion and child survival post-partum.

There are, however, promising practices to draw upon. HIV stigma reduction intervention strategies used in other settings could be applied to the PMTCT context. Emerging evidence reveals several key programmatic principals for successful stigma-reduction programs. We know that successful interventions involve a combination of strategies/approaches, engage a broad range of stakeholders, address intersecting stigmas, and are led by or actively engage communities experiencing stigma (Stangl et.al, 2010).

Current research suggests that stigma reduction interventions are most effective when stigma is addressed through a range and combination of approaches (Mahajan et al. 2008, Parker et al. 2003). Recent reviews have broken down stigma reduction interventions into four categories, including: (1) information-based approaches; (2) skills building; (3) counselling/support; and (4) contact with affected groups. These broad categories encompass a range of different intervention activities, such as training sessions, participatory learning, support groups, holding community meetings, using cultural mediums and media channels, and providing written materials with specific information of local relevance (Brown et al. 2003, Stangl et al. 2010). Evaluation data from stigma reduction interventions shows that the more activities a respondent reports exposure to, the larger the increase in awareness of stigma and decrease in fear and value-driven stigma (Nyblade et al. 2008). Multiple activities not only reinforce messages, but provide ongoing opportunities to engage on the issue, learn, and begin to change attitudes and behavior. In addition, different activities reach and appeal to different segments of the community.

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Promising interventions piloted in a wide range of contexts have demonstrated that another key element to successful stigma reduction programs is the involvement of gate keepers and multiple change agents, such as local government leaders, teachers, police, media, and healthcare providers (Apinundecha et al. 2007, Boulay et al. 2008, Young et al. 2010). Building commitment to and ownership of the stigma reduction process among community leaders is crucial for obtaining buy-in from the larger community. To cultivate community leaders as champions for stigma reduction, it is important to build their knowledge of HIV and stigma; provide opportunities for them to address their own fears, misconceptions and attitudes; and build their capacity to reduce stigma. These leaders help raise awareness and reduce fear within the community, facilitating a shift in community norms (Nyblade et al. 2008; Stangl et al. 2010). Shifting community norms is likely to inspire more lasting population-level improvement in community attitudes and create an enabling environment for PLHIV to engage in health care and social support systems. As evidence of this, Boulay and colleagues (2008) found that individuals living in communities with more positive attitudes towards PLHIV had significantly better attitudes towards PLHIV than people living in communities with less favourable attitudes.

Research has shown that it’s also important to address intersecting stigmas. Stigma and discrimination are particularly harsh for populations that are already socially excluded or have unequal status in society. These groups often experience stigma and discrimination based on intersecting stigmas related to gender, sexuality, ethnicity, etc. (Reidpath et al. 2005, Nyblade et al. 2006 , Loutfy et al. 2012, Logie et al. 2013). In the context of PMTCT it would be particularly important to address intersecting stigma related to gender. Women and children, for example, are more prone than men to property grabbing, abandonment and violence as a result of their HIV status (Swaminathan et al. 2008).

Lastly, evidence gathered from community-led interventions highlights the critical role that supportive networks play in helping strengthen capacity of marginalized communities to reduce stigma and discrimination. Involving marginalized communities is essential for strengthening capacity, ensuring appropriate messaging, and maximizing results (Stangl et al. 2010). Addressing self-stigma (the internalization of society’s negative attitudes) effectively is an important precondition for effective engagement of marginalized communities. (Rao et al. 2012).

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Neonatal Survival & Health

A lack of preventative practises in pregnancy such as iron intake, complications during pregnancy, delivery with unskilled attendants, and a lack of postnatal care all contribute to high rates of neonatal mortality, as well as to the number of children born with disabilities that can threaten their ability to thrive. Risk factors for neonatal death and disability are particularly evident among disadvantaged women living in poor-resource communities (D'Ambruoso 2012). Reducing the risk for death and poor health outcomes during infancy requires that care providers, particularly mothers, receive quality care at the prenatal, birth and postnatal stages (Bhutta et al. 2005).

The Lancet group (2005) reports that effective and low-cost interventions that increase the likelihood of neonatal survival and health do exist. Such interventions include promoting early initiation of breast-feeding, treating infections early with antibiotics, and training community-based health workers who oversee births to implement basic resuscitation strategies (Barros et al. 2012). However, such interventions are not frequently utilized. There are many barriers that interfere with access to care, and some of the most significant are associated with stigma and discrimination (Darak et al. 2012). Perceived stigma and the experience of discrimination in health facilities are particularly pernicious barriers to care for HIV-positive women (Rahangdale et al. 2010, Turan et al. 2012). The section following describes the evidence for effective and sustainable interventions that seek to address barriers associated with stigma and discrimination as a means to improve neonatal survival and health.

The evidence is moderate to weak as there is a paucity of research examining the effectiveness of programs that implement the aforementioned low-cost interventions to promote neonatal survival and health, particularly in developing countries (Schiffman et al. 2010). Moreover, only a handful of these studies systematically assess stigma and discrimination reduction as outcomes of the intervention approach. Studies of interventions that specifically target stigma and discrimination as a means to improve neonatal survival and health are virtually non-existent, except in the PMTCT literature that focuses on eliminating barriers that interfere with HIV positive women accessing care that prevents mother-to-child transmission of the disease.

The strongest evidence for interventions that target stigma and discrimination to increase neonatal survival and health arises from the PMTCT literature and is covered in detail in a different section of this report. As such it will not be reviewed in detail here. However, an important lesson learned from the PMTCT work that warrants mentioning here is that

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maternal health and newborn outcomes are inextricably linked (Futterman et al. 2010, Turan et al. 2011). As such, addressing stigma and discrimination at all stages leading up to the newborn's entry into the world, during delivery and, shortly after birth are critical to ensuring survival and good health outcomes among neonates.

The limited evidence that exists on stigma and discrimination reduction efforts that impact neonatal survival and health suggest that the provision of information in community settings is an important mechanism to increase knowledge among groups that typically underutilize available services and; increasing their knowledge can improve their access to care. For example, Kumar et al. (2012) report results of a cluster randomized control trial to assess the impact of a newborn-focused behavioral intervention on maternal health in rural communities in India. Results suggest that the provision of information promoting birth and emergency preparedness, and care seeking from trained providers improves equity in care provision across different religious and caste categories. Improvements were noted in maternal knowledge, behaviors (e.g. care seeking) and birth outcomes.

A reduction in stigma can also be achieved through interventions that attend to where and how information is provided. For example, capitalizing on social support structures appears to facilitate the acquisition of important information relevant for neonatal survival and health among women from disadvantaged backgrounds. There is some evidence from studies of disadvantaged groups in high-income countries that social support plays an important role in behavioral change in mothers. For example, the provision of social support during prenatal visits among Mexican immigrants increases the likelihood that participants in the intervention group would come in for a post-partum appointment. The provision of information to fathers regarding maternal care in some communities improves the chances of a safe delivery and implementation of good post-birth practices. In one study, implementing an intervention to provide men with information about maternal care in informal, community-based settings where they typically gather to interact socially was a good mechanism for reducing stigma (Nasreen et al. 2012).

Attending to service location is a widely advocated approach to improving access to care among disadvantaged groups that is centered around eliminating economic barriers. However, service location also has particular relevance in efforts to reduce stigma and discrimination. For example, research assessing the impact of PMTCT interventions suggests that location of services is important. HIV-positive women are reluctant to access services for a fear of stigma and discrimination in contexts that are clearly

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associated with being HIV positive. In high-income nations, there is increasing support for providing mental health services in schools as a mechanism for facilitating access to care among groups that typically will not access mental health care because of stigma (Clauss-Ehlers et al. 2012). With respect to neonatal survival and health, there has been a lot of advocacy for integrated services to enable a "one-shop stop" model where multiple services are accessed in a single location—all of which could contribute to improved maternal and neonatal outcomes.

There is also some evidence that interventions designed to reduce discriminatory practices among health-care providers are key to reducing neonatal health and survival. Discrimination against HIV-positive pregnant women attempting to access care is widely acknowledged in nations across the economic spectrum. A qualitative study of HIV-positive mothers attempting to access PMTCT care in India (Rahangdale et al. 2010) suggests that HIV-positive women perceive discrimination at multiple levels, including at the institutional level as well as in their interpersonal interactions with health workers. Turan et al. (2008) report findings from a qualitative study in a Kenyan community with a high rate of HIV infection and low rate of childbirth in a health setting. They conclude that sensitivity training, increasing knowledge and access to post-exposure prophylaxis among health workers may reduce their unwillingness to attend births of women who are or suspected to be HIV-positive, and also improve the quality of the care they provide. An important implication of this work is that PMTCT interventions should include efforts to reduce stigma at both the institutional and interpersonal level as a mechanism to promote the retention of HIV-positive women in programs that are key to ensuring neonatal survival and health.

Healthy Early Childhood Development

It is well documented that children's developmental outcomes are influenced both by biological and environmental factors. For example, poverty, family stress, caregiver health and mental health status, and exposure to violence have all been documented to have a deleterious impact on child development and subsequent adjustment (Barbarin et al. 2001, Barbarin and Richter 1999, Noble et al. 2005, Gottlieb and Blair 2004). The sequela of many of these risks to child developmental outcomes is stigma. There is very little evidence to support interventions that directly address the impact of stigma on children's developmental outcomes. As such, interventions to improve children's outcomes by reducing children's risk exposure and indirectly impacting stigma may

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constitute the best existing evidence. In this section we review selected evidence which addresses areas where stigma is a cross cutting issue.

Stigma and discrimination interventions likely to result in improved developmental outcomes in children arm families with an appropriate skill set (e.g. parenting skills); empower them with knowledge that helps them overcome personal and systemic barriers; and facilitate access to resources necessary for providing safe and health-promoting home environments for children. The evidence for effective and sustainable interventions that specifically address stigma and discrimination and achieve these goals is weak. Few studies examine specific strategies to overcome discrimination and stigma that directly impact children's developmental outcomes, and the studies that do tend not to be empirically strong. However, virtually all efforts to adapt interventions to local contexts, specific cultural groups or family types entail some consideration of issues related to stigma and discrimination. Furthermore, there is moderate evidence that there are interventions targeting stigma that yield positive attitudinal shifts and increased knowledge in families, care-providers and communities (Brown et al. 2003), and such changes can serve as the basis for behavioral changes that facilitate children's physical, cognitive and social growth.

Ecological perspectives suggest that stigma and discrimination reduction interventions can operate at the intrapersonal, interpersonal, and broader structural levels of the institution, community, and/or country). In their comprehensive review of literature on parenting, Richter and Naicker (2013), explain how interventions that are based in human rights and protection from discrimination can be important structural approaches that affect parenting. That is, parents find it very difficult to fulfill their parenting roles in countries where human rights abuses and discrimination are tolerated. These authors draw on studies that describe parents who experience discrimination in their communities as a result of color, caste, ethnicity, language, religion, sexual preference, sexual practice, drug use (see Rekart 2006, Beard et al. 2010, Rhodes et al. 2010) and state that supportive interventions "include self-help and solidarity, education and empowerment, care, decriminalization and legal representation, safety and protection, and community-based child protection networks" (p. 33).

Community-based interventions often address discrimination and improve equity by increasing service provision to underserved or marginalized groups. There are a few randomized control studies of community-level interventions for which stigma and discrimination reduction is not the focus, but often an added beneficial outcome. For example, in a randomized control study in rural communities in India, Pandey and

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colleagues (2007) demonstrate that the provision of information to community members about their entitlement to child-related services increased service delivery to potentially stigmatized groups (low caste) and may therefore have inadvertently addressed discrimination. Similarly, in a cluster randomized control trial the provision of information promoting birth and emergency preparedness, and care-seeking from trained providers improved maternal knowledge and care-seeking, and did so similarly across religious and caste categories (Kumar et al. 2012). As such, these interventions improved the capacity of families likely to experience stigma and discrimination, to access care for their children and thereby improve child health and developmental outcomes.

There is also limited evidence available on good parenting skills' interventions targeting stigma and discrimination in low-income countries. The majority of evidence that describe rigorous studies on parenting interventions is drawn from high-income countries; specifically those in Europe and North America. However, evidence from both low- and high-income countries demonstrates how poverty can significantly endanger the wellbeing of children and families (Yoshikawa et al. 2012). For example, Abosede et al. (2010) found in their Nigerian study, that poverty makes it difficult for disadvantaged parents to pay the high fees charged by child development centers. Early education centers have the promise for improving healthy child development through intensive stimulation and learning, and provide opportunities for poor mothers to gain income by working outside the home. These authors found that providing community support for free early education increased the likelihood that mothers would enroll their under-five children in the education program, and also increased their participation in income-generating work.

At the more proximal intra-personal level, maternal health and emotional status are known to affect infant functioning. Maternal depression is strongly associated with many risk factors (e.g., HIV infection, poverty) that may be stigmatized. The impact of maternal depression may be particularly powerful during the early years of life as this is a time when young children are more dependent on nurturance, stimulation and support from primary caregivers. Concomitant stigma associated with maternal risk factors for depression may exacerbate the impact of maternal depression on child outcomes. Tripathy and colleagues (2010) examined the role of participatory intervention with women's groups as a mechanism for reducing maternal depression in a rural population in three districts in Eastern India. In this randomized clinical trial women were assigned to either a control group or an intervention group where education about maternal and infant health was provided. Maternal outcomes including depression were monitored for both groups. A large and sustained reduction in maternal depression was observed in the

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intervention group. The authors suggested that social support for women in the intervention group resulted in reduced risk of depression and increased problem solving skills. While the intervention did not directly address stigma, empowering women to become more active participants in their health care may reduce barriers to care and potential for stigma.

Stigma is a significant barrier to healthy outcomes for people affected by HIV/AIDS. For families living with pediatric HIV, disclosure of the child's HIV status is a complex and often difficult process. Limited data from domestic studies suggest that contextual factors such as stigma and lack of social support influence caregiver's willingness or ability to disclose to their children. There has been limited evidence describing the development and evaluation of interventions to facilitate disclosure, and none directed specifically addressing stigma associated with HIV and disclosure. Blasini et al. (2004) developed a model to address many of the barriers to open communication about pediatric HIV. The investigators found that their model promoted healthy psychological adjustment and better adherence in children living with HIV. Nostlinger et al. (2004) note that disclosure of HIV status by parents to their children may promote improved developmental outcomes for children by reducing stigma. That is, dispelling misconceptions about the disease and fostering an openness that can help ameliorate the potential impact of stigma on children's developmental outcomes after their parents have died.

Nutrition

Our review noted the absence of interventions directly or indirectly addressing stigma in the domain of nutrition. We did not identify any study report that specifically addressed the stigmas around childhood nutrition although we did find intervention reports on stigmas around food insecurity more broadly (Dutta et al. 2012). Some studies tangentially reported the broader social and cultural contexts around childhood nutrition (Khatun et al. 2004). In other studies, context was addressed in the form of gender equity and empowerment (Ghosh et al. 2002, Khatun et al. 2004).

In their reporting of the effect of the BRAC initiative toward promoting gender and social equity in health, Khatun et al. (2004) reported that the intervention promoted gains in health among girls of BRAC mothers and a large proportion of the girls in the intervention group recovered from stunting (stunting here is seen as a proxy of deprivation, connected to lack of adequate nutrition). In addition, the results suggest that

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the intervention was related to equity in health between children from poor BRAC households and children from non-poor non-BRAC households. Although the intervention did not address stigma directly, it broadly addressed issues of gender equity and empowerment. However, given the absence of reporting regarding the specific intervention strategies, it is difficult to decipher the nature and scope of the intervention. It is also difficult to gauge what constitutes gender equity and gender empowerment in the ambit of the intervention and whether these relate to specific socially, culturally, and economically rooted stigmas.

Similarly, the Rural Unit for Health and Social Affairs run intervention addressed gender equity, women's empowerment, and economic and banking support in addition to offering extensive health services, health and nutrition education (Abel 1992). Once again, although stigma was not addressed directly, longitudinal measurement depicted reduction in severe malnutrition, infant mortality rate, and child mortality rate within the broader context of gender equity and women's empowerment. The reporting of the study did not provide detailed information on the gender equity and women's empowerment components of the intervention. Similarly, it is difficult to evaluate the specific messaging and framing strategies of the intervention from the intervention report.

Garg and Kashyap (2006) reported the effect of nutrition education on the quality and quantity of diets consumed. Although detailed information was not provided on the nutrition education component, the roles of husbands and mother-in-laws as change agents were discussed. Similarly, the Child in Need Institute (CINI) included the husband and mother-in-law in its behavior change communication component, and reported conducting its education programs in familial and community contexts (Chaudhuri 2002). Similarly, Abul-Fadl and colleagues (2012) document the positive role of husbands as sources of emotion and tangible support in a relactation intervention. Here, we note that although a key contextual feature is recognized, it is not analyzed in detail in the intervention or the intervention report. In reporting the CINI intervention, Chaudhuri (2002) notes the broader context of patriarchy and status of women in Indian society although she does not specifically document the role of these contexts in the intervention.

Similarly, in their report of a nutrition education program in rural India, Ghosh, Kilaru & Ganapathy (2002) briefly note the existence of discrimination against women but do not then provide any additional information and do not include this element into their intervention design. However, they do report differential impact of the intervention on feeding practices for girls and boys, with girls reporting improvements in weight gain. They suggest that perhaps due to culturally rooted preference for sons, the feeding

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practices for boys did not change much as they were closer to the recommended behaviors. However, these links and contextual features are not really empirically tested and documented.

In the realm of breastfeeding, Abul-Fadl and colleagues (2012) note the negative role played by the surrounding social network of family and friends. In the report, the authors suggest that in the vulnerable state post-pregnancy, even mothers who are knowledgeable become susceptible to the lack of information or negative attitudes toward breastfeeding in the support network. The negative support information received from family and friends can work as detriment to breastfeeding, thus suggesting the need for adequate counseling and positive support.

In many other instances however, nutrition education efforts did not really address either direct or indirect aspects of stigma and marginalization. In the broader domain of food insecurity, Dutta and colleagues (2013) reported an intervention in the US that directly addressed the stigma around food insecurity, documenting qualitative indicators such as greater access to food pantries and greater quality of food available in the food pantries among the food insecure resulting from the intervention. The intervention, designed in a culturally centered process by the food insecure specifically focused on the food insecurity experienced by a growing number of families in the US and was built around the message, "food insecurity could happen to anybody." In the intervention, the participation of the food insecure in the development of the intervention led to the concept that addressing stigma around food insecurity is pivotal to addressing the issues of food insecurity in the community. Drawing from the observation made by the food insecure in the Dutta et al. (2013) project, we note the absence of the voices and participation of the communities experiencing malnutrition from reports of intervention design. It may be argued that this absence is itself stigmatizing as well as a marker of stigma (Dutta, 2012).

The relationship of nutrition to the broader sociocultural and economic context is also documented in some literature. That childhood nutrition impacts health outcomes as well as other social and economic outcomes is documented in some literature. For instance, Alderman, Hoogeveen, & Rossi (2008) analyze the data from a panel of children in Tanzania to document that children who are malnourished have lower schooling and delay their schooling entry. The authors also suggested the impact of malnutrition on the lack of economic opportunity. Similarly, in a report of Jamaican studies in nutrition and child development, Grantham-McGregor and Cumper (1992) noted the association between malnutrition and school achievement. We recommend the need for

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systematically documenting the relationship of malnutrition to the broader social, cultural and economic outcomes. This is important in understanding the cycles of disenfranchisement and marginalization that are connected to childhood malnutrition. This is also important in understanding how stigmatization plays out in cycles of poverty and structural in access, manifested in early childhood in a variety of experiences including malnutrition and with consequences for the rest of the life cycle.

Additional research needs to systematically evaluate the ways in which nutrition interventions address the broader socio-cultural contexts of nutrition. Similarly, intervention reports needs to offer more information on the specific aspects of the intervention that relate to stigmatization and marginalization and the specific elements of message design addressing the relational contexts of interventions. We observe the need for intervention reporting to offer in-depth intervention about the contextual features and the ways in which these features are configured in the intervention. More qualitative research documenting in-depth the norms, practices and values around nutrition are needed to offer clearer insights into the contexts surrounding nutrition.

Similarly, our comprehensive literature review documented gaps in the literature addressing stigmas related to poverty and lack of access to adequate nutrition. For instance, we were unable to identify a single communication intervention that was focused on addressing stigma around poverty. We also did not find a study that sought to address societal, cultural and community-based stigmas around the poor. These are areas of research and intervention planning that need to be looked into.

We did observe some examples of nutrition interventions that address the broader social determinants underlining the lack of access to nutrition. Although economic access to resources is a key element in addressing nutrition, this is missing from most intervention reports. In the case of the nutrition intervention offered by CINI, Chaudhuri (2002) discusses creating access to resources and linkages with key political sectors when needed, but does not really describe this component of the intervention in depth. Kalavathi et al. (2010) reported an intervention addressing nutrition gardening, livestock rearing, product diversification and allied income generation mechanisms in small and marginal coconut homesteads in Kerala, India, and documented change in poverty level as well as food insecurity in the community. King'olla, Ohiokpehai & David reported a nutrition and health program in Suba district, Kenya, documenting slight improvement in income level. However, because of the absence of a control community, we can't ascribe causality to the intervention. Similarly, Olney and colleagues (2009) reported the effects of a homestead food production program in Cambodia, documenting greater earned

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income, greater number of household owned animals, and greater production and consumption of micronutrient-rich food in the intervention households.

Marginalized Groups & Child Survival

Marginalized groups have decreased access to health services. They have limited resources and consequent high relative risk for morbidity and premature mortality (Flaskerud et al. 1998). In turn, children of parents belonging to marginalized groups have decreased access to health services and increased morbidity and mortality. As a consequence, 'unhealthy' birth spacing, diarrheal diseases and pneumonia disproportionately affecting poor and marginalized groups.

In many developing countries, the poor and the marginalized are often uninformed of the mortality and morbidity risks associated with short childbearing intervals. They may understand generally that spacing pregnancies is a healthy behavior, but most do not know that mortality, morbidity, and poor nutritional status are often associated with short birth intervals, and are preventable. In addition, some women may not know that they can control the pace of births, and may be unaware of the various options to achieve longer childbearing intervals, including: breastfeeding; modern contraceptive methods; abstinence; and natural family planning (Norton et al. 2005).

Diarrhea and acute respiratory infections are other examples of health issues that disproportionately affect poor and marginalized groups. Millions of children die unnecessarily from pneumonia and diarrhea, and mortality from these illnesses is increasingly concentrated in resource-poor settings (Walker et al. 2013). In fact, pneumonia and diarrhea are the leading causes of preventable deaths for children living in the world's poorest countries. Many interventions to prevent diarrhea and pneumonia exist within present health systems, but their coverage and availability to poor and marginalized populations varies greatly (Gill, et al. 2013).

Access to health services is a human rights issue. Human rights principles dictate the necessity to strive for equal opportunity for health for children and parents who suffer marginalization or discrimination. Braveman et al. (2003) suggest that governance and health institutions deal with marginalization, poverty and health within a framework encompassing equity and human rights concerns by implementing equitable health care financing (which should help reduce poverty while increasing access to health services for the poor, including children living in poverty); ensuring that health services respond

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effectively to the major causes of preventable ill-health among poor and disadvantaged children and adults; and taking action to address the potential health equity and human rights implications of policies in all sectors affecting health (Braveman et al. 2003).

Three Millennium Development Goals deal with combatting extreme poverty and improving children's life chances through access to education and health information and services. In 2012, countries committed to implement a "social protection floor" which would guarantee that their populations have access to a basic package of health, education and income benefits. If implemented equitably and inclusively, such high level policy interventions can overcome discrimination and exclusion of stigmatized groups, and create an enabling environment for behaviors which improve child health and development.

Concluding Remarks

Despite the broad consensus on the importance of stigma and discrimination as a potential barrier to access and uptake of any health information and services, this review found suprsingly little empirical research that directly addresses stigma, discrimination and child health in low and middle income countries.

This is partly a matter of semantics. There is a wealth of research demonstrating that poverty and social exclusion impede adult access to health information and services, as well as to the education and skills relevant to family planning, child rearing, nutrition, health promotion, disease prevention, and uptake of health care. However, there is a failure to connect such exclusion and disadvantage to the social and political distinctions, prejudices, stereotypes and "shame and blame" that are the heart of stigma research. There is also a substantial body of research that demonstrates that a number of intervention strategies can be effective to overcome discrimination and increase inclusiveness in allocation of social services. These include information education and communication, skills-building, community mobilization and mutual support, and strategic advocacy for equity, participation, and human rights.

The bulk of research directly on stigma and global health has focused on HIV. There has been significant increase in quantitative as well as qualitative research on interventions to combat stigma and discrimination, but little of it connects stigma with child health directly. The two topics where this has been explored directly are:

orphans and vulnerable children; and prevention of mother to child transmission of HIV (PMTCT). In these areas there is weak to moderate evidence of the effectiveness of interventions addressing stigma on outcomes.

The paucity of strong evidence, despite widespread consensus on the importance of the issue, is the result of several factors: anti-stigma interventions are often poorly described; interventions addressing stigma are usually part of a larger package, so that parsing out the effect of the anti-stigma element is difficult; and there is a lack of standardization in definitions and measurement of stigma and discrimination which impedes meta-analysis and learning from program experience. Furthermore, while the causal chain linking structural and individual factors to stigma marking, to felt and enacted stigma, to stigma manifestations, and finally to negative health outcomes is increasingly clear, that causal chain is long and complex, and few studies endeavour to tackle its entirety. It can be argued that to achieve population level changes that support child health interventions, the structural factors may be our most important target. Yet stigma and discrimination tends to be studied largely in small-scale projects, and structural factors such as policies and laws are rarely included in studies of anti-stigma interventions (Sengupta et al, 2011).

Stigma related to HIV is part of a larger picture of inequity due to marginalization; although this was not a direct focus of the review, results of the review suggest that addressing access and empowerment related to marginalization can mitigate improve child health outcomes in marginalized populations.

Recommendations

For health and development programs to be rights-based and people-centered, they must be alert to, and prepared to combat, ignorance, fear and social judgment that lead to stigma and discrimination. This means that increased attention to stigma and discrimination is needed in all domains affecting child health. This is ERT5's over-arching recommendation. Concern and action on stigma and discrimination may have arisen in the global HIV movement, but the ethical concerns and the structure of stigma processes and responses are general, and should be assimilated into child health research and practice. To accomplish this overarching recommendation, ERT5 makes four additional specific recommendations:

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2. For this to happen efficiently, a consensus conceptual model of stigma and anti-stigma interventions is needed, to support a common language, as well as standardized measures of stigma levels and processes. ERT5 recommends that the Summit calls for development of such a model that addresses the specific and actionable challenges in promoting child health and development. This model should:
   i. articulate the pathway connecting structural and individual causes and impacts;
   ii. support identification of standard , core measures of stigma causes and outcomes, including felt stigma, enacted stigma, and structural facilitators;
   iii. address relevant program areas beyond those directly related to HIV/AIDS prevention and treatment – nutrition, healthy early childhood development, immunize-able diseases;
   iv. explicitly include interventions that affect children by reducing consequences of stigma for their parents;
   v. explicitly include interventions addressing pathways through which stigma influences outcomes, such as disclosure, adherence, access and empowerment; and
   vi. include red flags and guidance regarding ethical issues and ways to avert stigma as a negative unintended consequence of interventions;
   vii. be developed with full participation of affected community members.

3. ERT5 recommends increased investment in stigma interventions and program evaluation. In order to overcome the evidence gap regarding anti-stigma interventions, ERT 5 recommends that planners prioritize regular inclusion of measures that assess stigma and discrimination in evaluations of all interventions targeting neonatal and child health and healthy early childhood development, including interventions addressing integrated care of mother and child. This will be facilitated by the aforementioned consensus about measures of stigma and discrimination.

4. Improve reporting about communication interventions – create a standard such as the CONSORT statement (http://www.consort-statement.org/).

5. Continue research to document the relational and sociocultural contexts of stigma surrounding interventions to improve child health. Beyond the documentation of the effects numerically, we note the need for more qualitative in-depth data that offer contextual information as well as richer insights into the structural aspects of stigma surrounding child nutrition, healthy early childhood development and immunization.

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References

Abel, R. RUHSA-a model primary health care program. Journal of Tropical Pediatrics 1992; 38(5), 270-273.

Abosede AO, Campbell PC, Okechukwu EI, Salako-Akande AO, Onyenwenyi AO. Sustainable poverty amelioration through early life education in a peri-urban community of Lagos,Nigeria. African Journal of Primary Health Care & Family Medicine 2010; 2 (1): 1-8.

Abul-Fadl AM, Kharboush I, Fikry M, Adel M. Testing communication models for relactation in an Egyptian setting. Breastfeed Med. 2012 Aug; 7:248-54.

Alderman H, Hoogeveen H, Rossi M. Reducing child malnutrition in Tanzania. Combined effects of income growth and program interventions. Econ Hum Biol. 2006 Jan;4(1):1-23.

Ali A, Hassiotis A, Strydom A, King M. Self stigma in people with intellectual disabilities and courtesy stigma in family carers: a systematic review. Res Dev Disabil 2012; Nov-Dec;33(6):2122-40

Apinundecha C, Laohasiriwong W, Cameron MP, Lim S. A community participation intervention to reduce HIV/AIDS stigma, Nakhon Ratchasima province, northeast Thailand. AIDS Care. 2007;19:1157-1165.

Awiti UO, Ekstrom AM, Ilako F, Indalo D, Wamalwa D, Rubenson B. Reasoning and deciding PMTCT-adherence during pregnancy among women living with HIV in Kenya. Cult Health Sex. 2011;13:829-840.

Barros AJ, Ronsmans C, Axelson H, Loaiza E, Bertoldi AD, França GV, Bryce J, Boerma JT, Victora CG. Equity in maternal, newborn, and child health interventions in Countdown to 2015: a retrospective review of survey data from 54 countries. Lancet 2012; 379(9822):1225-1233

Barbarin OA. Social risks and child development in South Africa: a nation's program to protect the human rights of children. Am J Orthopsychiatry. 2003 Jul;73(3):248-54.

Barbarin OA, Richter L, deWet T. Exposure to violence, coping resources, and psychological adjustment of South African children. Am J Orthopsychiatry. 2001 Jan;71(1):16-25.

Barbarin OA, Richter L. Economic status, community danger and psychological problems among South African children. Childhood. 2001;8(1):115-133.

Barbarin OA, Richter L. (1999). Adversity and psychosocial competence of South African children. American Journal of Orthopsychiatry 1999; 69:319–327

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Beard J, Biemba G, Brooks MI, Costello J, Ommerborn M, Bresnahan M, Flynn D, Simon JL. Children of female sex workers and drug users: a review of vulnerability, resilience and family-centred models of care. J Int AIDS Soc. 2010 Jun 23;13 Suppl 2:S6.

Beard J, Feeley F, Rosen S. Economic and quality of life outcomes of antiretroviral therapy for HIV/AIDS in developing countries: a systematic literature review. AIDS Care. 2009 Nov;21(11):1343-56.

Bhutta ZA, Darmstadt GL, Haws RA, Yakoob MY, Lawn JE. . Delivering interventions to reduce the global burden of stillbirths: improving service supply and community demand. BMC Pregnancy and Childbirth,2009; 9 Suppl 1:S7.

Bhutta ZA, Darmstadt GL, Hasan BS, Haws RA. Community-based interventions for improving perinatal and neonatal health outcomes in developing countries: a review of the evidence. Pediatrics. 2005 Feb;115(2 Suppl):519-617.

Blasini I, Chantry C, Cruz C, et al. (2004). Disclosure model for pediatric patients living with HIV in Puerto Rico: design, implementation, and evaluation. *J. Dev. Behav. Pediatr*. 25:181-189.

Boulay M, Tweedie I, Fiagbey E. The effectiveness of a national communication campaign using religious leaders to reduce HIV-related stigma in Ghana. Afr J AIDS Res 2008; 7(1):133- 141.

Boyes ME, Mason SJ, Cluver LD. Validation of a brief stigma-by-association scale for use with HIV/AIDS-affected youth in South Africa. AIDS Care 2013; 25(2):215-22

Braveman, P, Gruskin, S. Defining Equity in Health. Journal of Epidemiology and Community Health 2003; 57(4)

Brown L, Macintyre K, Trujillo L. Interventions to Reduce HIV/AIDS Stigma: What Have We Learned? AIDS Educ Prev 2003; 15(1):49-69.

Buyse D, Nuwaha F, Karlin T, Wilfert C. Prevention of mother-to-child transmission of HIV: from research to action. 2006.

Bwirire LD, Fitzgerald M, Zachariah R et al. Reasons for Loss to Follow-up among Mothers Registered in a Prevention-of-Mother-to-Child Transmission Program in Rural Malawi. Transactions of the Royal Society of Tropical Medicine and Hygiene. 2008;102:1195-1200.

Castro, A, Farmer, P. Understanding and Addressing AIDS-Related Stigma: From Anthropological Theory to Clinical Practice in Haiti. American Journal of Public Health 2005; 95(1):53-59.

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Chaudhuri, SN. CINI's approaches to intervention: an innovative strategy to combat malnutrition in India. Nutr Rev 2002; 60(5 Pt 2), S102-108.

Claus-Ehlers et al 2012

Cluver L, Orkin M, Boyes ME, Sherr L, Makasi D, Nikelo J. Pathways from parental AIDS to child psychological, educational and sexual risk: Developing an empirically-based interactive theoretical model. Soc Sci Med. 2013 Jun;87:185-93.

Cluver L, Orkin M. Cumulative risk and AIDS-orphanhood: interactions of stigma, bullying and poverty on child mental health in South Africa. Soc Sci Med. 2009 Oct; 69(8):1186-93

Cluver L, Gardner F. Risk and protective factors for psychological well-being of children orphaned by AIDS in Cape Town: a qualitative study of children and caregivers' perspectives. AIDS Care. 2007Mar;19(3):318-25

Cluver L, Bowes L, Gardner F. Risk and protective factors for bullying victimization among AIDS-affected and vulnerable children in South Africa. Child Abuse Negl. 2010 Oct; 34(10):793-803.

Cluver L. Children of the AIDS pandemic. Nature. 2011 Jun; 2;474(7349):27-9.

Cluver LD, Gardner F, Operario D. Effects of stigma on the mental health of adolescents orphaned by AIDS. J Adolesc Health. 2008 Apr; 42(4):410-7.

Coetzee D, Stringer E, & Chi BH. (2009). Evaluation of PMTCT coverage in four African countries: the PEARL study. Paper presented at the 5th IAS Conference on HIV Pathogenesis and Treatment.

Courtwright A, Turner AN. Tuberculosis and stigmatization: pathways and interventions. Public Health Reports 2010; Suppl 4:34-42.

D'Ambruoso L. Relating the construction and maintenance of maternal ill-health in rural Indonesia. Glob Health Action. Aug 2012; 5. doi: 10.3402/gha.v5i0.17989.

Darak S, Panditrao M., Parchure R, Kulkarni V, Kulkarni S, & Janssen F. Systematic review of public health research on prevention of mother-to-child transmission of HIV in India with focus on provision and utilization of cascade of PMTCT services. BMC Public Health. 2012; 12: 320.

Darmstadt GL, Lee AC, Cousens S, Sibley L, Bhutta ZA, Donnay F, Osrin D, Bang A, Kumar V, Wall SN, Baqui A, Lawn JE.International Journal of Gynaecology and Obstetrics: the Official Organ of the International Federation of Gynaecology and Obstetrics 2009; 107 Suppl 1:S89-112.

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Duff, P., Kipp, W., Wild, T. C., Rubaale, T., & Okech-Ojony, J. (2010). Barriers to accessing highly active antiretroviral therapy by HIV-positive women attending an antenatal clinic in a regional hospital in western Uganda. J Int AIDS Soc, 13, 37.

Dutta MJ, Anaele A, & Jones C. (2013). Voices of hunger: Addressing health disparities through the culture-centered approach. Journal of Communication 2013; 63, 159-180.

Dutta M J. Hunger as health: Culture-centered interrogations of alternative rationalities of health. Communication Monographs 2012; 79, 366-384.

Ekouevi DK, Leroy V, Viho I et al. Acceptability and uptake of a package to prevent mother-to-child transmission using rapid HIV testing in Abidjan, Cote d'Ivoire. AIDS. 2004;18:697-700.

Finlayson K, Downe S. Why Do Women Not Use Antenatal Services in Low- and Middle-Income Countries? A Meta-Synthesis of Qualitative Studies. PLoS Med 2013; 10(1): e1001373. doi:10.1371/journal.pmed.1001373

Flaskerud, J, Winslow, B. Conceptualizing vulnerable populations health-related research. Nurs Res 1998; 47(2):69-78.

Foster G, Williamson J. A review of current literature on the impact of HIV/AIDS on children in sub-Saharan Africa. AIDS 2000; 14 suppl 3: S275-84.

Futterman, D, Shea J, Besser M, Stafford S, Desmond K, Comulada W S, Greco E. Mamekhaya: A pilot study combining a cognitive-behavioral intervention and mentor mothers with PMTCT services in South Africa. AIDS Care 2010; 22(9), 1093-1100.

Garg A, Kashyap S. Effect of counseling on nutritional status during pregnancy. Indian J Pediatr. 2006 Aug;73(8):687-92.

Ghosh S, Kilaru A, Ganapathy S. Nutrition education and infant growth in rural Indian infants: Narrowing the gender gap? Journal of the Indian Medical Association 2002; 100(8), 483-490.

Giddens A. The Constitution of Society: Outline of the Theory of Structuration. University of California Press. 1984

Gill,C, Young, M, Schroder, K, Carvajal-Velez, L, McNabb, M, Aboubaker, S, Qazi, S, Bhutta, Z. Bottlenecks, barriers, and solutions: results from multicountry consultations focused on reduction of childhood pneumonia and diarrhoea deaths. The Lancet 2013; 381(9876):1487-1498

Goffman E. Stigma -Notes on the Management of Spoiled Identity. Simon & Schuster 1963

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Gottlieb G, Blair C. How early experience matters in intellectual development in the case of poverty. Prev Sci. 2004 Dec;5(4):245-52.

Grantham-McGregor S, Cheung Y B, Cueto S, Glewwe P, Richter L, Strupp B, International Child Development Steering. . Developmental potential in the first 5 years for children in developing countries. Lancet 2007;, 369(9555), 60-70. doi: 10.1016/s0140-6736(07)60032-4

Grantham-McGregor S M, Cumper G. Jamaican studies in nutrition and child development, and their implications for national development. Proceedings of the Nutrition Society 1992; 51(1), 71-79.

Kalavathi S, Krishnakumar V P, Thomas R J, Thomas G V, & George M L . Improving food and nutritional security of small and marginal coconut growers through diversification of crops and enterprises. Journal of Agriculture and Rural Development in the Tropics and Subtropics 2010; 111(2), 101-109.

Khatun M, Stenlund H, Hörnell A. BRAC initiative towards promoting gender and social equity in health: A longitudinal study of child growth in Matlab, Bangladesh. Public Health Nutrition2003; 7(8), 1071-1079.

Khumalo-Sakutukwa G, Morin SF, Fritz K, Charlebois ED, van Rooyen H, Chingono A, Modiba P, Mrumbi K, Visrutaratna S, Singh B, Sweat M, Celentano DD, Coates TJ; NIMH Project Accept Study Team. Project Accept (HPTN 043): A community-based intervention to reduce HIV incidence in populations at risk for HIV in sub-Saharan Africa and Thailand J Acquir Immune Defic Syndr. 2008 Dec 1;49(4):422-31

King'olla B, Ohiokpehai O, Mbithe D D . The impact of a nutrition and health program on the socio-economic status and food access of households in Suba District, Kenya. Journal of Applied Biosciences 2009; 21, 1226-1236.

Kleinman A. The social course of epilepsy: chronic course of illness as social experience in interior China. Chapter 7, pp. 147-172, In: Kleinman, A. Writing at the Margins: Discourse between Anthropology and Medicine. Berkeley: University of California Press, 1995.

Kuhn L, Coovadia HM. Protecting infants of HIV-positive mothers in Malawi. The Lancet. 2012.

Kumar V, Kumar A, Das V, Srivastava NM, Baqui AH, Santosham M, Darmstadt GL; Saksham Study Group. Community-driven impact of a newborn-focused behavioral intervention on maternal health in Shivgarh, India. Int J Gynaecol Obstet. 2012 Apr; 117(1):48-55.

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Logie C, James L, Tharao W, Loutfy M. Associations between HIV-related stigma, racial discrimination, gender discrimination, and depression among HIV-positive African, Caribbean, and Black women in Ontario, Canada. AIDS Patient Care STDs 2013; 27(2):114-122.

Loutfy MR, Logie CH, Zhang Y, Blitz SL, Margolese SL, Tharao WE, et al. Gender and ethnicity differences in HIV-related stigma experienced by people living with HIV in Ontario, Canada. PLoS One 2012; 7(12):e48168.

Mahajan AP, Sayles JN, Patel VA, Remien RH, Sawires SR, Ortiz DJ, et al. Stigma in the HIV/AIDS epidemic: a review of the literature and recommendations for the way forward. AIDS 2008; 22(Supplement 2):S67-S79.

Mepham S, Zondi Z, Mbuyazi A, Mkhwanazi N, Newell ML. Challenges in PMTCT antiretroviral adherence in northern KwaZulu-Natal, South Africa. AIDS Care. 2011;23:741-747

Nasreen HE, Leppard M, Al Mamun M, Billah M, Mistry SK, Rahman M, Nicholls P. Men's knowledge and awareness of maternal, neonatal and child health care in rural Bangladesh: a comparative cross sectional study. Reprod Health. 2012 Sep; 3;9:18.

Noble, K.G., Norman, M.F., & Farah, M.J. (2005). Neuro- cognitive correlates of socioeconomic status in kindergarten children. *Developmental Science,* 8 (1), 74–87.

Norton, M. New evidence on birth spacing: promising findings for improving newborn, infant, child, and maternal health. Int J Gynaecol Obstet 2005; 89(1):S1-S6

Nöstlinger C, Jonckheer T, de Belder E, van Wijngaerden E, Wylock C, Pelgrom J, Colebunders R. Families affected by HIV: parents' and children's characteristics and disclosure to the children. AIDS Care. 2004 Jul;16(5):641-8

Nyblade L, Hong KT, Anh NV, Ogden J, Jain A, Stangl A, et al. Communities Confront HIV Stigma in Viet Nam: Participatory Interventions Reduce HIV-Related Stigma in Two Provinces. Washington, DC; Hanoi, Vietnam: International Center for Research on Women (ICRW); Institute for Social Development Studies (ISDS); 2008. pp. 1-37.

Nyblade L. Measuring HIV Stigma: Existing Knowledge and Gaps. Psychology, Health and Medicine 2006; 11(3):335-345.

Oanh, K. T. H., Ashburn, K., Pulerwitz, J., Ogden, J., and Nyblade, L. Improving Hospital-based Quality of Care in Vietnam by Reducing HIV-related Stigma and Discrimination, a Horizons Final Report. 2008. Washington, DC, Population Council.

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O'Driscoll C, Heary C, Hennessy E, McKeague L. Explicit and implicit stigma towards peers with mental health problems in childhood and adolescence. J Child Psychol Psychiatry. 2012 Oct; 53(10):1054-62

Olney D K, Talukder A, Iannotti L L, Ruel M T, Quinn V. Assessing impact and impact pathways of a homestead food production program on household and child nutrition in Cambodia. Food and Nutrition Bulletin 2009; 30(4), 355-369.

Painter TM, Diaby KL, Matia DM et al. Sociodemographic factors associated with participation by HIV-1-positive pregnant women in an intervention to prevent mother-to-child transmission of HIV in Cote d'Ivoire. Int J STD AIDS. 2005;16:237-242.

Pandey P, Sehgal AR, Riboud M, Levine D, Goyal M. Informing resource-poor populations and the delivery of entitled health and social services in rural India: a cluster randomized controlled trial. JAMA. 2007 Oct 24;298(16):1867-75.

Parker R, Aggleton P. HIV and AIDS-Related Stigma and Discrimination: A Conceptual Framework and Implications for Action. Soc Sci Med 2003; 57(1):13-24.

Pulerwitz J, Michaelis A, Weiss E, Brown L, Mahendra V. Reducing HIV-related stigma: lessons learned from Horizons research and programs. Public Health Rep 2010 Mar-Apr; 125(2):272-81.

Rahangdale L, Banandur P, Sreenivas A, Turan JM, Washington R, Cohen CR. Stigma as experienced by women accessing prevention of parent-to-child transmission of HIV services in Karnataka, India. AIDS Care 2010; 22(7): 836-842.

Rao D, Desmond M, Andrasik M, Rasberry T, Lambert N, Cohn SE, et al. Feasibility, Acceptability, and Preliminary Efficacy of the Unity Workshop: An Internalized Stigma Reduction Intervention for African American Women Living with HIV. AIDS Patient Care STDs 2012.

Reidpath DD, Chan KY. A Method for the Quantitative Analysis of the Layering of HIV-Related Stigma. AIDS Care 2005; 17(4):425-432.

Rekart ML. Sex-work harm reduction. Lancet. 2005 Dec; 17;366(9503):2123-34

Rhodes T, Bernays S, Houmoller K. Parents who use drugs: accounting for damage and its limitation. Soc Sci Med. 2010 Oct;71(8):1489-97.

Richter, L. M. & Naicker, S (2013). *A Review of Published Literature on Supporting and Strengthening Child-Caregiver Relationships (Parenting)*. Arlington, VA: USAID's AIDS Support and Technical Assistance Resources, AIDSTAR-One, Task Order 1.

The views expressed in this document do not necessarily reflect the views of the agencies and organizations that employ the authors or of any of the sponsors for the U.S. Government Evidence Summit on Enhancing Child Survival and Development in Lower- and Middle-Income Countries by Achieving Population-Level Behavior Change.

Schiffman J, Darmstadt GL, Agarwal S, Baqui AH (2010). Community-based intervention packages for improving perinatal health in developing countries: a review of the evidence. Seminars in Perinatology 2010; 34(6): 462-476]

Sengupta S, Banks B, Jonas D, Miles MS, Smith GC. HIV interventions to reduce HIV/AIDS stigma: a systematic review. AIDS Behav. 2011 Aug;15(6):1075-87

Stangl A, Carr D, Brady L, Eckhaus T, Claeson M, Nyblade L. Tackling HIV-Related Stigma and Discrimination in South Asia. Washington, DC: World Bank; 2010.

Swaminathan H, Walker C, Rugadya MA. Women's Property Rights, HIV and AIDS & Domestic Violence: Research Findings from Two Districts in South Africa and Uganda. South Africa: HSRC Press; 2008.

Tripathy P, Nair N, Barnett S, Mahapatra R, Borghi J, Rath S, Rath S, Gope R, Mahto D, Sinha R, Lakshminarayana R, Patel V, Pagel C, Prost A, Costello A. Effect of a participatory intervention with women's groups on birth outcomes and maternal depression in Jharkhand and Orissa, India: a cluster-randomised controlled trial. Lancet. 2010 Apr 3;375(9721):1182-92.

Tsai AC, Weiser SD, Steward WT, Mukiibi NF, Kawuma A, Kembabazi A, Muzoora C, Hunt PW, Martin JN, Bangsberg DR. Evidence for the reliability and validity of the internalized AIDS-related stigma scale in rural Uganda. AIDS Behav. 2013 Jan;17(1):427-33

Turan JM, Bukusi EA, Onono M, Holzemer W L, Miller S, Cohen CR.. HIV/AIDS stigma and refusal of HIV testing among pregnant women in rural Kenya: results from the MAMAS Study. AIDS Behav 2011; 15(6), 1111-1120. doi: 10.1007/s10461-010-9798-5

Turan JM, Nyblade L. HIV-related stigma as a barrier to achievement of global PMTCT and maternal health goals: A review of the evidence. AIDS Behav 2013 online March 2013

UNAIDS.2007. *Reducing HIV Stigma and Discrimination:a critical part of national AIDS programmes*. Geneva: Joint United Nations Programme on HIV/AIDS.2007

UNAIDS. 2012. PCB Submissions on Thematic Segment – Non discrimination. December 13, 2012.UNAIDS/PCB(31)/12.25

Young SD, Konda K, Caceres C, Galea J, Sung-Jae L, Salazar X, et al. Effect of a Community Popular Opinion Leader HIV/STI Intervention on Stigma in Urban, Coastal Peru. AIDS Behav 2010;:1-8

The views expressed in this document do not necessarily reflect the views of the agencies and organizations that employ the authors or of any of the sponsors for the U.S. Government Evidence Summit on Enhancing Child Survival and Development in Lower- and Middle-Income Countries by Achieving Population-Level Behavior Change.

van Brakel WH, Sihombing B, Djarir H, Beise K, Kusumawardhani L, Yulihane R, Kurniasari I, Kasim M, Kesumaningsih KI, Wilder-Smith A. Disability in people affected by leprosy: the role of impairment, activity, social participation, stigma and discrimination. Glob Health Action. 2012;5

Viteva E. Impact of stigma on the quality of life of patients with refractory epilepsy. Seizure. 2013 Jan;22(1):64-9

Walker, C, Rudan,I, Liu,L, Nair, H, Theodoratou, E, Bhutta, Z, O'Brien, K, Campbell, H, Black, R. Global Burden of Childhood Pneumonia and Diarrhoea. The Lancet 2013.

Watts C, Zimmerman C, Eckhaus T, Nyblade L. Modelling the impact of stigma on HIV and AIDS programs: preliminary projections for mother to child transmission. 2010. Washington, D.C., International Center for Research on Women (ICRW).

WHO. Programmatic Update Use of Antiretroviral Drugs for Treating Pregnant Women and Preventing HIV Infection in Infants. Executive Summary. 2012.

Yoshikawa H, Aber JL, Beardslee WR. The effects of poverty on the mental, emotional, and behavioral health of children and youth: implications for prevention. Am Psychol. 2012 May-Jun;67(4):272-84

Young SD, Konda K, Caceres C, Galea J, Sung-Jae L, Salazar X, Coates T. Effect of a community popular opinion leader HIV/STI intervention on stigma in urban, coastal Peru. AIDS Behav. 2011 Jul;15(5):930-7.

DRAFT

The views expressed in this document do not necessarily reflect the views of the agencies and organizations that employ the authors or of any of the sponsors for the U.S. Government Evidence Summit on Enhancing Child Survival and Development in Lower- and Middle-Income Countries by Achieving Population-Level Behavior Change.