



# Understanding the Social Stigma of Fetal Alcohol Spectrum Disorders: From Theory to Interventions

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## Abstract

Alcohol consumption during pregnancy can lead to fetal alcohol spectrum disorders (FASD). FASD is a spectrum of structural, functional, and neurodevelopmental problems with often lifelong implications, affecting communities worldwide. It is a leading preventable form of intellectual disabilities and therefore warrants effective prevention approaches. However, well-intended FASD prevention can increase stigmatization of individuals with FASD, women who consume or have consumed alcohol during pregnancy, and non-biological parents and guardians of individuals with FASD. This narrative review surveyed the literature on stigmatization related to FASD. Public stigma appears to be the most common form of stigma studied. Less is known about FASD-related self-stigma, stigma by association, and structural stigma. Accordingly, the current literature on FASD-related stigma does not appear to provide sufficient guidance for effectively reducing FASD-related stigma. However, lessons can be learned from other related health topics and the use of a systematic approach for the development of health promotion programs, namely Intervention Mapping.

**Keywords** Stigma · Pregnancy · Fetal alcohol spectrum disorders · Prevention · Alcohol

## 1 Introduction

Alcohol consumption during pregnancy puts an unborn child at risk for a range of structural, functional, and often lifelong deficits that can be grouped under the category fetal alcohol spectrum disorders (FASD). FASD is an umbrella term covering the following diagnostic categories: fetal alcohol syndrome (FAS), partial fetal alcohol syndrome (pFAS), alcohol-related neurodevelopmental disorder (ARND), alcohol-related birth defects (ARBD), or neurobehavioral disorder with prenatal alcohol exposure (ND-PAE)

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(American Psychiatric Association 2013; Hoyme et al. 2016). Studies addressing FASD prevalence have shown that this spectrum of disorders is a burden for societies worldwide (Popova et al. 2017; Roozen et al. 2016b). As such, FASD is an important health concern for which prevention is needed (Popova et al. 2017; Roozen et al. 2016a, b).

To date, there is no known amount of alcohol that is safe to drink during pregnancy (Roozen et al. 2018). Research has, however, shown that binge drinking, defined as more than three standard drinks per occasion, is an important risk factor for FASD (May et al. 2005). Also, lower amounts of alcohol can have serious consequences for the development of an unborn child (Mamluk et al. 2017). Research demonstrating the harmful effects of alcohol consumption during pregnancy has been followed by several actions to create awareness about prenatal alcohol exposure and FASD (e.g., warning labels on alcohol beverages, media campaigns). These actions have often included messages advising women not to consume alcohol during pregnancy. Consequently, attitudes towards pregnant women who consume alcohol have changed over the years. Today, women who consume alcohol during pregnancy, and/or have a child with FASD, and individuals with FASD, are often stigmatized (Armstrong and Abel 2000; Bell et al. 2016; BMA Board of Science 2016; Corrigan et al. 2017; Elliott et al. 2006; Hoyme et al. 2016; Jacobs and Jacobs 2014; Montag 2016; Mukherjee et al. 2015; Schölin 2016; WHO 2014, 2017; Zizzo and Racine 2017).

Stigmatization is a social and culturally constituted process whereby a person is first identified as different and then devalued, leading to status loss and discrimination (Bos et al. 2013; Dovidio et al. 2011). From a social cognitive perspective, the process of stigmatization comprises thoughts in the form of stereotypes, emotional reactions in the form of prejudice, and behavior in the form of discrimination (Pryor and Bos 2015). Various individuals can experience stigma related to FASD. First, women who consume or have consumed alcohol during pregnancy can be held responsible for drinking alcohol during pregnancy and can therefore be blamed for having a child with FASD. Second, non-biological parents and guardians of individuals with FASD can be held responsible for a child with FASD's disability or behavioral difficulties. Third, individuals with FASD can be perceived as frequent users of social services due to their medical and social problems.

Stigmatization related to FASD can have far reaching consequences whereby, for example, biological mothers of children with FASD fear societal judgement and thus conceal having consumed alcohol during pregnancy (BMA Board of Science 2016). Women might also be reluctant to seek counselling or treatment for alcohol dependence (Clement et al. 2015; WHO 2014).

In this article, we provide a narrative review of the literature on stigmatization related to FASD. We first describe different types of FASD-related stigma and then address ways in which FASD-related stigma can be reduced. We subsequently discuss Intervention Mapping as a useful framework for the development of theory- and evidence-based FASD-related stigma reduction programs. Lastly, we conclude with theoretical and practical recommendations.

## 2 Method

A literature search was conducted in PubMed, PsychINFO, PsychARTICLES, ERIC, CINAHL, EMBASE, and MEDLINE databases for articles published before January 2020 using a search query including synonyms of the following keywords: FASD (e.g., fetal

alcohol exposure, fetal alcohol spectrum disorders), pregnancy (e.g., maternal, prenatal), behavior (e.g., alcohol consumption, drink), and stigma (e.g., stereotype, prejudice, discrimination). The query of keywords was iteratively updated when new synonyms were encountered. Studies were considered when published in English and when they reported any description of FASD-related stigma.

### 3 Results

#### 3.1 FASD-Related Stigma

From the literature, we can distinguish four types of stigma: public stigma, self-stigma, stigma by association, and structural stigma (Pryor and Reeder 2011). These four types of stigma are interrelated (see also Fig. 1). However, public stigma is considered to be at the core of the other three types of stigma (Pryor and Reeder 2011).

##### 3.1.1 Public Stigma

Public stigma represents people's cognitive, affective, and behavioral reactions to a person they perceive to have a stigmatized condition (Bos et al. 2013). As indicated above, three groups of individuals can be subjected to public stigma in the context of FASD:

*Women who consumed alcohol during pregnancy* frequently experience stigmatization. Corrigan et al. (2019) reported a number of stereotypes about biological mothers of children with FASD. Biological mothers of children with FASD are frequently construed as bad parents, neglectful parents, child abusers, or addicts. They are also often seen as being in denial or secretive about their alcohol dependence, and as responsible for negative health outcomes in their children or, alternatively, ignorant about the negative health outcomes of alcohol consumption during pregnancy. They are further construed as people with poor social connections and low socioeconomic positions who have a personal history of maltreatment leading to alcohol dependence, as well as poor prognosis for recovery from alcohol dependence. Importantly, biological mothers of children with FASD are considered to be deserving of harsh judgment. Additionally, Corrigan et al. (2017) ascertained that the more people know about FASD, the more likely they are to endorse the stigmatization of biological mothers of children with FASD. Clearly, women who consumed alcohol during

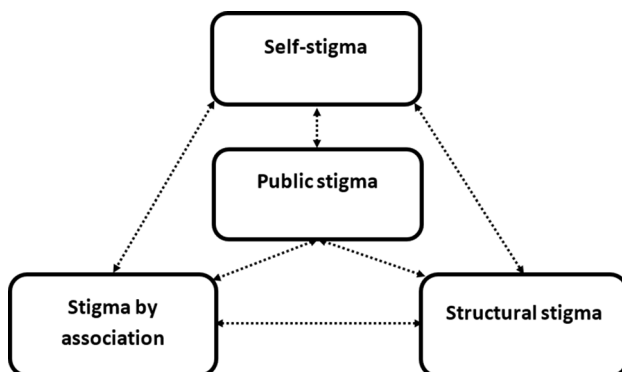


Fig. 1 Types of stigma adapted from Pryor and Reeder (2011) and Bos et al. (2013)

pregnancy are often perceived as being morally culpable for a child's prenatal exposure to alcohol and ensuing FASD (Bell et al. 2016). There thus appears to be a clear discourse of agency whereby pregnant women with alcohol dependence are perceived to lack 'self-control' and 'voluntarily' consume alcohol during pregnancy (Racine et al. 2015), resulting in blaming and shaming (Bell et al. 2016; Davis and Manago 2016).

The public stigma of women who consume or have consumed alcohol during pregnancy is thus perpetuated by simplified beliefs about substance use dependence whereby people with problematic alcohol use are considered personally responsible for the onset and offset of their alcohol dependence (Racine et al. 2015; Stutterheim et al. 2016). This predominantly moral view of alcohol dependence is increasingly being replaced by biological explanations for alcohol dependence (Racine et al. 2015). However, research has shown that biological explanations are not a "magic bullet solution" that circumvents stigmatization. Biological explanations have—albeit less intentionally—also been found to contribute to the public stigma of women who consume or have consumed alcohol during pregnancy (Hammer et al. 2013; Racine et al. 2015).

*Non-biological parents and guardians of children with FASD* can also experience stigmatization. There is literature showing that non-biological parents of children with FASD have been held responsible for their child's disabilities (Bell et al. 2016; Corrigan et al. 2017). Women have reported feeling blamed when their child showed difficult behavior, stating that others would likely consider them to be bad parents (Mukherjee et al. 2013).

*Individuals with FASD* are also subject to stigmatization. These individuals are often perceived to "place a drain on society" due to their medical and social problems (Bell et al. 2016, p. 4). According to Corrigan et al. (2018), stereotypes about children with FASD are that they are different than normal people, that they are brain disordered, that prognosis is bad, and that facial abnormalities are characteristics of FASD. Children with FASD are also seen as having significant difficulties with attention, learning, and the formation of social relations. Additionally, they are often stereotyped as 'retarded', 'immature', 'lazy', and 'violent'.

Children with FASD are often socially excluded, particularly at school. They frequently struggle to make friends and their behavior is considered to be problematic by teachers and administrators (Bell et al. 2016). This often leads to reduced self-esteem, low self-confidence, and increased social isolation (Salmon and Buetow 2012). Their self-esteem and potential to succeed are further impeded by beliefs that individuals with FASD will inevitably be societal failures who will likely engage in criminal behavior and, fueled by biological explanations for substance use dependence, use drugs or alcohol (Bell et al. 2016; Shankar 2016).

Given this, it is not surprising that individuals with FASD have reported feeling misunderstood, underestimated, disrespected, bullied, and blamed for the challenges they face (Bell et al. 2016; Copeland 2002). Indeed, studies have reported that individuals with FASD are sometimes viewed as purposefully misbehaving (Sanders and Buck 2010) demonstrating that FASD-related difficulties such as difficulties perceiving social cues and poor judgement are often attributed to the person rather than the disability (Gardner 2000). Although individuals with FASD are not considered to be personally responsible for having acquired FASD, they are nonetheless considered difficult and, unjustifiably, are often held responsible for their apparent inability to offset the negative consequences of FASD (Bell et al. 2016; Dej 2011).

Public stigma towards women who consumed alcohol during pregnancy, non-biological parents and guardians of individuals with FASD, and individuals with FASD have been reflected in *mass media* (Armstrong and Abel 2000; Aspler et al. 2019; Eguigaray et al. 2016), often in the form of well-intended prevention messages. Eguigaray et al. (2016) explored the framing of FASD-related media coverage in Australia and found that

messages about FASD were framed in two ways. The first kind of messages were sympathy-framed messages. These messages showed empathy for mothers in vulnerable positions, and sympathy towards children and adults with FASD, by positioning children as victims of their mother's behavior during pregnancy (e.g., "babies pay for bad habits", "unfairly punished"). Also, there have been messages directed towards generating sympathy for all individuals with FASD, framed as, for example, "a humanitarian crisis" or "a hidden disability". The second kind of prevention messages were shame-framed messages directed towards mothers, healthcare professionals, and governmental agencies. In these messages, mothers were portrayed negatively and blamed for, for example, "being selfish" or having knowingly put their unborn child at risk. Healthcare professionals were blamed for not raising concerns about alcohol consumption with pregnant patients, and the government was critiqued through messages depicting the lack of policy support and governmental actions (e.g., "cone of silence"). In similar vein, Aspler et al. (2019) analyzed the content of newspaper articles mentioning FASD in Canada for key themes. They identified three topics of ethical concern that can lead to stigmatization. These were (i) exaggeration of FASD prevalence estimates observed in Indigenous communities; (ii) conflicting information on the harmful effects of alcohol; and (iii) narrow scientific information. Both Aspler et al. (2019) as well as Eguiagaray et al. (2016) pointed to the need to be more cognizant of the possible negative effects of FASD prevention messages.

FASD-related public stigma is pervasive and has far-reaching consequences. A study conducted by Corrigan et al. (2017) shows that people have high intentions to stigmatize. In this study, participants were first asked to rate levels of difference, disdain, and responsibility on four conditions, namely mental illness, substance use disorder (alcohol or other drugs), incarceration, and FASD. Subsequently, participants were asked to allocate budget for 10 human service programs. This task is a frequently used proxy of discrimination. The results showed that mothers of children with FASD were considered more different, disdained, and responsible than women with serious mental illness, substance use disorder, or jail experience. FASD was also allocated less budget than all other human services programs proposed. This is strong empirical evidence that the stigma of FASD is pervasive and severe. Similarly, in a study on models of stigma towards biological mothers of children with FASD, Key, Ceremony, and Vaughn (2019) found that participants who attributed controllability for alcohol consumption to biological mothers were also less willing to help biological mothers of children with FASD.

Clearly, public stigma impedes support for parents and guardians of a child with FASD. Various studies have shown that, for parents and guardians of individuals with FASD, soliciting help from support networks is difficult because parents often feel misunderstood (Sanders and Buck 2010). Accessing professional support is also impeded by the public stigma of FASD. Healthcare professionals often lack knowledge about FASD and its challenges (Mukherjee et al. 2013; Sanders and Buck 2010; Whitehurst 2012), which can leave families dealing with FASD feeling misunderstood (Mukherjee et al. 2013). Additionally, discrimination on the part of healthcare professionals undermines the services that children with FASD and their biological mothers receive (Corrigan et al. 2019).

### 3.1.2 Self-Stigma

Unfortunately, negative beliefs and attitudes about women who consumed alcohol during pregnancy and individuals with FASD are not limited to the domain of others (public stigma); they are also anticipated, expected, and internalized by individuals with FASD

and their mothers. This is called self-stigma. *Self-stigma* reflects the social and psychological impact of having a stigma. It includes both the anticipation of being stigmatized and the internalization of the negative beliefs and feelings associated with the stigmatized condition (Bos et al. 2013).

Self-stigma involves self-blame and feelings of shame. Research has shown that biological mothers of children with FASD engage in self-blame and hold themselves responsible for the outcomes of prenatal exposure to alcohol, even in cases when they were unaware of the effects of such exposure (Armstrong and Abel 2000; Shankar 2016; Wood 2010).

Some women do report having consumed alcohol during pregnancy because they believe that one glass of alcohol would not put their child at risk or because family, friends, and healthcare professionals told them that it is fine to drink modestly during pregnancy, often because they too drank modestly during pregnancy (Coathup et al. 2017; Holland et al. 2016; Loxton et al. 2013), reflecting that the harmful effects of prenatal alcohol consumption have not always been known or recognized (Warren 2015). Armstrong and Abel (2000), as well as Zobotka et al. (2017) and others have reported biological mothers of individuals with FASD regret drinking alcohol during pregnancy and feel guilty about the outcomes of alcohol consumption during pregnancy. In this context, biological mothers of individuals with FASD tend not to acknowledge the broader social and structural factors (e.g., poverty, poor access to treatment, and other forms of marginalization) that potentially contributed to their alcohol use during pregnancy, but rather focus on personal responsibility (Salmon 2008; Shankar 2016). This is disadvantageous because self-blame has been found to impede parent–child relationships (Masood et al. 2007), and thus can contribute to decreased successful adjustment for individuals with FASD. Self-stigma in women at risk for having a child with FASD can also impede support seeking (Clement et al. 2015). Studies have shown that feelings of guilt can lead to inaccurate reporting of drinking patterns for fear of being judged (Bearer et al. 2003; Bell et al. 2016; Eguiagaray et al. 2016; Lange et al. 2014; Montag 2016).

Self-stigma also occurs in individuals with FASD when they internalize negative beliefs about FASD, and can lead to an underestimation of one's own potential (Stade et al. 2010). Difficulties forming friendships and negative feelings about behavior perceived as problematic by others is often internalized, leading to lower self-esteem and lower self-confidence (Salmon and Buetow 2012).

### 3.1.3 Stigma by Association

The stigma of FASD can also extend to associates of individuals with FASD and potentially also to people connected with women who consume or have consumed alcohol during pregnancy. *Stigma by association* includes social and psychological reactions to being associated with a stigmatized person as well as people's reactions to being associated with a stigmatized person (Bos et al. 2013; Pryor et al. 2012). Biological mothers of children with FASD who are primary caregivers to their child with FASD are subjected to a double burden. Not only are they stigmatized directly for having consumed alcohol in pregnancy, they are often also stigmatized as a result of their association with their child with FASD and his or her accompanying behavioral problems or disabilities (Davis and Manago 2016; Pereira 2010; Salmon 2008). Additionally, stigma by association is felt by non-biological parents and guardians who can, as a result of FASD-related stigma, feel compelled to

disclose that their child was adopted in order to avoid blame and stigmatization (Whitehurst 2012).

Stigma by association has severe consequences for families. The lack of support and guidance that is generated by stigma by association often leaves parents desperate, stressed, and anxious (Olson et al. 2009; Whitehurst 2012). For some families, the stigma by association leads to social isolation and fear of what the future might bring (Gardner 2000; Mukherjee et al. 2013; Whitehurst 2012). These negative consequences have also been found for stigma by association in the context of other stigmatized conditions, such as mental illness (Van der Sanden et al. 2013).

### 3.1.4 Structural Stigma

Lastly, there is structural stigma surrounding FASD. *Structural stigma* is stigma that is reflected, legitimized, and perpetuated by society's institutions and ideological systems (Bos et al. 2013). The current literature points to three main issues that contribute to FASD-related structural stigma.

The first is coercive or punitive measures that aim to reduce prenatal alcohol exposure, such as compulsory reporting, removal of the parental rights, and criminalization of women who consume alcohol during pregnancy (Racine et al. 2015). These kinds of measures are often driven by ideological systems with strong fetus protection and right to life movements but are highly detrimental to the reduction of FASD-related stigma, and the prevention and identification of FASD (Racine et al. 2015). Such measures are certainly not universal, and legislation varies from country to country, but many countries have legislation related to child welfare, and civil or criminal liability for harm, that can be engaged to attribute blame and responsibility, thus criminalizing alcohol consumption during pregnancy and furthering structural stigma of biological mothers of individuals with FASD (Roozen et al. 2017). For example, in the United States, there is a wide range of state-level policies relevant to FASD. Some policies are supportive, focusing on early intervention and the provision of treatment facilities, but others are punitive, claiming, for example, that alcohol exposure to an unborn child is child abuse or neglect. Defining alcohol exposure as child abuse or neglect (i.e., punitive approach) criminalizes mothers and clearly perpetuates stigma.

The second major form of structural stigma is the use of public health initiatives that, in seeking to reduce prenatal alcohol exposure, promote negative judgments of alcohol use in pregnancy, and emphasize 'risk' to the child and 'responsibility' of the mother as an individual (Bell et al. 2016; Racine et al. 2015; Shankar 2016). Well-intended supportive approaches, such as providing information about the harmful effects of alcohol use during pregnancy can also lead to blame, particularly when framed negatively (e.g., "women should not drink during pregnancy"; Meurk et al. 2014). Public health messages often include warnings that there is no known amount of alcohol safe to drink during pregnancy and that alcohol can result in irreversible damage to the unborn child (Shankar 2016). According to Zizzo and Racine (2017), such messages promoting abstinence are unlikely to be optimal as they threaten women's autonomy. Also, abstinence might not be feasible for all pregnant women due to substance use dependence, low risk perceptions, a lack of self-efficacy, and perceived norms that consuming alcohol during pregnancy is common (Coathup et al. 2017; Crawford-Williams et al. 2015; Holland et al. 2016; Meurk et al. 2014; van der Wulp et al. 2015).



In addition to risk information, many public health campaigns present FASD as a preventable spectrum of disorders, which can lead to significant victim-blaming and most certainly ignores the complexity of potential factors that lead some women to consume alcohol during pregnancy. In some public health campaigns, additional focus is placed on the greater impact of FASD via, for example, messages about the financial and societal costs of FASD (Shankar 2016). Clearly, these kinds of public health efforts can seriously undermine the provision of effective support services to women who use alcohol during pregnancy and individuals with FASD (Bell et al. 2016; Racine et al. 2015; Shankar 2016). Communication about a health problem can unintentionally provoke stigma and, across stigmatized conditions, there is often a tension between prevention and stigma (Millum et al. 2019; Smith et al. 2016), whereby public health messages that emphasize personal responsibility for a condition often inadvertently contribute to public stigma (Riley et al. 2017; Young et al. 2016). One way to circumvent this is to combine threat information with a positive message that promotes self-efficacy (France et al. 2014). In the context of FASD prevention, this is a matter of communicating what pregnant women can do rather than what they should not do.

A third issue that contributes to structural stigma is marginalization. Efforts seeking to reduce prenatal alcohol exposure tend to obscure systemic structural social inequalities and environmental conditions that contribute to prenatal alcohol exposure. FASD-related stigma is driven and compounded by multiple forms of marginalization, including health inequalities (Racine et al. 2015). A lack of support provision for individuals with FASD and their parents and/or caregivers can be considered an example of inequality (Mukherjee et al. 2013).

### 3.2 Reducing FASD-Related Stigma

Evidently, in light of the above, stigma reduction efforts are warranted. However, although several review articles on stigma reduction strategies have been published (Cook et al. 2014; Heijnders and Van Der Meij 2006; Rao et al. 2019), there is currently very little literature on effective stigma reduction for FASD-related stigma. How the various forms of stigma—public stigma, stigma by association, self-stigma, and structural stigma—can effectively be reduced are explored below.

#### 3.2.1 Reducing Public Stigma and Stigma by Association

Most FASD-stigma reduction interventions have focused on public stigma, and analogously, stigma by association as the determinants of for both forms of stigma are similar. Parents and caregivers can experience both public stigma and stigma by association. As put forth in a recently published review article by Rao et al. (2019), FASD-related stigma necessitates multilevel approaches targeting not only the individual (e.g., people experiencing stigma), but also interpersonal (e.g., family members), community (e.g., healthcare professionals), organizational (e.g., social marketing), and structural (e.g., governmental policies) levels.

In general, two strategies for reducing public stigma are distinguished in the literature: education and interpersonal contact (Corrigan et al. 2012; Pettigrew and Tropp 2006). Several meta-analyses have been published on the effects of education and contact on public stigma, most of which focus on using these interventions to reduce mental illness stigma. For example, Griffiths, Carron-Arthur, Parsons, and Reid (2014) conducted a meta-analysis



on the basis of 33 randomized control trials for interventions aiming to reduce mental illness stigma, and found that interventions involving contact with a person with mental illness were more effective in reducing stigmatizing attitudes and social distance than educational interventions (Griffiths et al. 2014). Similarly, Corrigan et al. (2012) conducted a meta-analysis of 72 studies, of which 13 were randomized control trials, and concluded that contact interventions were more effective than educational interventions in reducing stigmatizing attitudes and behavioral intentions to stigmatize (Corrigan et al. 2012). A subsequent meta-analysis of the interventions that included a follow-up measure also showed that, at follow-up, contact interventions were still more effective than educational interventions in reducing stigmatizing attitudes (Corrigan et al. 2015). More recently, Morgan et al. (2018) conducted a meta-analysis that included 62 randomized control trials of contact interventions, educational interventions, and mixed contact and education interventions, as well as family psychoeducation programs and hallucination simulations. They found that both contact interventions and educational interventions had small to medium immediate effects on stigmatizing attitudes and social distance. Interestingly, combined education and contact interventions appeared to be similarly effective to interventions that focus only on education or only on contact. When only education and only contact interventions were compared, no clear advantage of one or the other was established (Morgan et al. 2018), which is in contrast to Corrigan et al. (2012, 2015).

Although no meta-analysis on the effectiveness of stigma reduction strategies for FASD-related stigma have been conducted, some evaluations of interventions seeking to address public stigma towards pregnant women with substance use dependence have been conducted (Bland et al. 2001; Meng et al. 2007; Ramirez-Cacho et al. 2007). In these studies, medical students received an educational program and were subsequently put in direct contact with pregnant women with alcohol dependency, followed by a series of measures reflecting increased ease in talking with pregnant women with alcohol dependency and greater perceived ability to treat these women's specific needs.

The first study was conducted by Bland et al. (2001). In their study, 84 medical students followed a five-week course on human reproduction with a special focus on substance use dependence. The course consisted of three parts including a simulated patient encounter, a lecture on the effects of drugs and alcohol use in pregnancy, and a problem-based tutorial about a young pregnant woman with alcohol use dependence. Changes in attitudes were ascertained using a questionnaire measuring comfort levels in discussing substance use with patients, general attitudes towards substance use and patients with substance use dependence, and attitudes towards substance use in pregnancy. The results showed no changes in general attitudes toward substance use and patients with substance use disorders but the educational program did appear to improve students' levels of comfort in discussing substance use with patients and their attitudes towards substance use in pregnancy.

Later, Ramirez-Cacho et al. (2007) set out to determine the impact of medical students working in a clinic for pregnant women with substance use dependence as clerks and found that this experience led to changes in students' attitudes towards pregnant women with substance use dependence. Compared to a control group, students who had completed a clerkship in a clinic and had been put in direct contact with pregnant women with substance use dependence showed a significant improvement in comfort levels. Additionally, students who had taken part in the clerkship reported being less judgmental when treating pregnant women with substance use dependence than beforehand. Furthermore, the clinical experience brought about subtle changes in attitudes with students who had had contact with pregnant women with substance use dependence reporting, after the clerkship, more agreement with statements that non-physician counsellors can provide effective treatment for

pregnant women with substance use dependence and that substance use during pregnancy is a common problem in our society. They also reported increased confidence in their ability to treat women using substances in a non-judgmental way.

In a similar study investigating if attending a specialized prenatal clinic would lead to changes in medical students' comfort levels and attitudes towards pregnant women with alcohol dependence, Meng et al. (2007) found improvements in students' level of comfort toward pregnant women with alcohol dependence and greater disagreement with the statement that alcohol dependence is due to a weak will.

In sum, these studies provide some insight on how the stigmatization of women who consume alcohol during pregnancy can be reduced. Unfortunately, to date, there is no literature that focuses specifically on how to best reduce stigma towards parents and guardians, including adoptive mothers and fathers, of individuals with FASD, and individuals with FASD themselves.

### 3.2.2 Reducing Self-Stigma

There are currently no published studies on self-stigma reduction interventions for mothers of children with FASD or for individuals with FASD. However, there are interventions for reducing self-stigma related to substance use dependence and insights from these studies could be helpful in ascertaining how to best tackle self-stigma related to FASD. For example, Livingston et al. (2012) identified group-based Acceptance and Commitment Therapy as a promising intervention for reducing self-stigma in people with substance use dependence. Additionally, self-stigma reduction approaches used for other stigmatized conditions, such as mental illness stigma, could also serve as an example for FASD self-stigma reduction interventions (e.g., Alonso et al. 2019; Mittal et al. 2012; Yanos et al. 2015). Most of these interventions use psycho-education or techniques from cognitive behavioral therapy to debunk myths about mental illness and to prevent or combat the internalization of negative beliefs about people with mental illness (i.e., public stigma; Mittal et al. 2012; Yanos et al. 2015). Another approach focuses on empowerment. For example, the Honest, Open, and Proud program developed by Corrigan et al. (2013) is a three-session peer-led group intervention that seeks to eliminate self-stigma by supporting people with mental illness in their disclosure decision-making processes. Research has demonstrated that this intervention is successful in reducing self-stigma among people with mental illness (Corrigan et al. 2013; Mulfinger et al. 2017). Despite the limited amount of knowledge in the field of FASD-related self-stigma reduction strategies, studies from related fields (e.g., mental health) could be helpful.

### 3.2.3 Reducing Structural Stigma

Although efforts to reduce public and self-stigma are commendable, these are likely to be less effective if structural stigma is present. Stigma reduction on a structural level can be accomplished by, for example, changing social norms and policies (Hatzenbuehler and Link 2014). Hatzenbuehler claims that reducing structural stigma, and its effects, requires the development of structural interventions (Hatzenbuehler 2016) but in doing so, we must be cognizant of possible unintended negative consequences of structural approaches. Unfortunately, across stigmatized conditions and identities, evidence for interventions that effectively reduce structural stigma is rather limited.

More broadly, research has shown that, in order to achieve structural change, it is important to select theory- and evidence-based methods for structural change via, for example, public policy (Kok et al. 2016). Examples of structural change methods include media advocacy, agenda setting, timing to coincide with policy windows, and creating and enforcing laws and regulations. The effectiveness of these methods is dependent on the extent to which these methods' theoretical parameters for use or effectiveness are taken into account when developing structural level interventions. For example, agenda setting requires appropriate timing and collaboration with gatekeepers whereby often persuasive communication and consciousness-raising are necessary (Kok et al. 2016). Additionally, the development of evidence-based reduction strategies for the reduction of structural stigma is multidimensional. For example, policy change requires a multilevel perspective that makes use of various effective behavior change methods across individual, organizational, and community levels (Hatzenbuehler and Link 2014; Kok et al. 2016). As such, methods for structural change also demand the use of individual level change methods (targeting public stigma) such as attitude change and collective efficacy (see for instance Knai et al. 2010).

### 3.3 Developing Theory-and Evidence-Based Interventions to Reduce FASD-Related Stigma

Changing FASD-related stigma is challenging as the origin of FASD-related stigma lies in the perceptions and beliefs held about women who consume or have consumed alcohol during pregnancy and about individuals with FASD. These perceptions and beliefs are likely to trigger emotional and behavioral reactions, which subsequently contribute to stigmatization and discrimination (Corrigan 2002; Pryor and Bos 2015). Using a social cognitive model of stigma, Corrigan (2002) set out to describe the relationship between stigmatizing attitudes and discriminatory behavioral responses (e.g., avoidance). Similar, Key et al. (2019) investigated explanations for the relationship between beliefs and behaviors through the attribution model and via the stereotype content model. However, to date, there remains no integrative theory explaining how beliefs lead to behavior (Peters and Crutzen 2018). What we do know from psychological theory is that, in order to effectively reduce stigma, we must first identify the specific determinants of that stigma (Bos et al. 2008) and then effectively employ stigma reduction methods in ways that take their parameters for use or effectiveness into account (Kok et al. 2016). Additionally, previous studies have reported that programs are most likely to be effective when they are developed systematically using theory and evidence-based methods (Bos et al. 2008).

Intervention Mapping is a theory and evidence-based systematic planning approach for behavior change interventions that guides intervention developers and implementers via a six step framework for effective decision-making (Bartholomew Eldredge et al. 2016; Kok et al. 2016; Roozen et al. 2016a). The Intervention Mapping protocol describes a path from problem identification to problem mitigation. Each of the six steps comprises several tasks, and each integrates theory and evidence. The completion of the tasks within a step creates a product that is the guide for the subsequent step but it is normal to move back and forth between the steps as the intervention is planned. At the end of the six steps, intervention developers have a blueprint for the design, implementation, and evaluation of an intervention that is based on a foundation of theoretical, empirical, and practical information. The six steps, and their related tasks, are as follows: In Step 1, planners develop a logic model of the problem. This involves conducting a needs assessment or problem analysis where planners identify what, if anything, needs to be changed, and for whom. Step 2 involves

ascertaining program outcomes and objectives for each stage of the logic model of change. Here, matrices of change objectives are drafted by combining the desired (sub-)behaviors with their determinants in order to identify what needs to change in a given determinant in order to achieve the desired (sub-)behaviors. Step 3 is program design, which entails selecting theory-based intervention methods that match the determinants into which the identified beliefs aggregate, and then translating these into practical applications that satisfy the parameters for effectiveness of the selected methods. Step 4 focuses on program production, where the practical applications are organized into a coherent program. Step 5 involves developing a program implementation plan for the adoption, implementation, maintenance and sustainability of the program in real-life contexts. This includes identifying program users and supporters, and determining what their needs are, and how these needs can be met. Step 6 involves the production of an evaluation plan so that effect and process evaluations can be carried out to measure program effectiveness and appropriateness. Overall, Intervention Mapping holds significant promise for stigma reduction in the context of FASD. If we follow the steps of Intervention Mapping, employ theory and/or evidence-based stigma reduction strategies, and take their parameters for use and effectiveness into account when we apply them in a coherent program, significant strides in reducing FASD-related public stigma, stigma by association, self-stigma, and structural stigma can be made. For the future of research and practice in this field, several recommendations are formulated.

### 3.4 Recommendations for Research and Practice

The results of this narrative review show that there is literature on FASD-related stigma but this literature is still in its infancy. However, from the studies available, and leaning on insights from other stigmatized conditions or identities, several recommendations can be made. First, there is clear a need for FASD-related stigma reduction programs that focus on, and provide support to, women who consume or have consumed alcohol during pregnancy and parents, including adoptive parents, of individuals with FASD, and individuals with FASD. Second, in order for stigma reduction efforts to be successful, a sound framework for intervention planning that uses a theory and evidence to systematically develop stigma reduction programs is needed (Mittal et al. 2012). Intervention Mapping offers significant promise in this regard. Third, systematically developed interventions should be carefully piloted and evaluated for their applicability, effectiveness, and generalizability. Fourth, interventions must be developed in collaboration with those targeted and affected by interventions (Dalky 2012; Livingston et al. 2012).

In terms of future research, further investigation of the effectiveness of stigma reduction strategies is needed, particularly in the field of FASD. In conducting these studies, it is important to pay attention to methodological challenges (e.g., substantial variation in methodological operationalizations, taking care of follow-up assessments, and avoiding small sample sizes) (see also Mak et al. 2017). It is also important to include a measure of “real” behavioral change as studies often do not assess the extent to which the intended programs challenged the participants’ behavior in a real world setting (Dalky 2012).

Specifically, with respect to better understanding public stigma, and the impact and repercussions of public stigma, we recommend investigating beliefs held by the general population about alcohol dependence, women who use alcohol during pregnancy, and FASD. In this regard, stereotype endorsement, perceptions of agency, attitudes towards women who use alcohol during pregnancy, and endorsement of coercive policies against

women who use alcohol while pregnant are worthy of investigation. It would also be interesting to explore the role of gender and how views of mothers and fathers of children with FASD differ. With regard to self-stigma, we recommend further exploring the extent to which society's negative beliefs and attitudes about FASD are anticipated and internalized by women who consume or have consumed alcohol during pregnancy and by individuals with FASD, as well as the ways in which stigma anticipation and internalization impact on psychological and social well-being. Moreover, this kind of research would benefit from a delineation of the different kinds of support needed by women who consume or have consumed alcohol during pregnancy and by individuals with FASD, in order to effectively promote resilience against the insidious effects of stigmatization. Research efforts should also prioritize further investigation of stigma by association as experienced by those connected to individuals with FASD. There is a paucity of research in this regard, and it would be worthwhile to look not only at how birth mothers are affected by direct stigmatization but also at the effects of stigmatization as a result of having a child with disabilities and/or behavioral problems. Furthermore, we recommend investigating the unique experiences of individuals with FASD, of biological mothers, of fathers, and of adoptive parents. Lastly, we recommend the identification of structures that contribute to FASD-related stigma. We contend that it is important to explore how coercive policies contribute to stigma, and it is important to identify means of structural support for the reduction of FASD-related stigma. Additionally, research should explore how public health prevention goals can be met without stigmatizing women who consume alcohol during pregnancy. Finally, there is a need for a greater understanding of how FASD-related stigma layers with other forms of marginalization that are linked to race, class, and ethnicity.

In sum, we believe that these proposed recommendations for practice and research can contribute to stigma reduction. If we apply theory- and evidence-based interventions for stigma reduction across interpersonal, intrapersonal, and structural domains, we can reduce FASD-related stigma, and in turn, also FASD.

## Compliance with Ethical Standards

**Conflict of interest** The authors declare no conflict of interest.

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