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To cite this article: Patrick W. Corrigan, Binoy Biren Shah, Juana Lorena Lara, Kathleen T. Mitchell, Peggy Combs-Way, Diana Simmes & Kenneth L. Jones (2018): Stakeholder perspectives on the stigma of fetal alcohol spectrum disorder, *Addiction Research & Theory*, DOI: [10.1080/16066359.2018.1478413](https://doi.org/10.1080/16066359.2018.1478413)

To link to this article: <https://doi.org/10.1080/16066359.2018.1478413>



Published online: 18 Jun 2018.



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ORIGINAL ARTICLE



## Stakeholder perspectives on the stigma of fetal alcohol spectrum disorder

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### ABSTRACT

**Background:** Fetal Alcohol Spectrum Disorder (FASD) is a condition afflicting children born to women who consumed alcohol during pregnancy that can lead to secondary disabilities including cognitive and social deficits. Both, children with FASD, and their biological mothers, are targets of FASD stigma. This study seeks to identify stereotypes, prejudice, and discrimination corresponding to FASD stigma.

**Methods:** Nine stakeholders comprised a community based participatory research (CBPR) team to discuss logistics, identify focus groups, and develop a qualitative interview guide. Attitudes and beliefs regarding children with FASD and their biological mothers were obtained from four focus groups of people: adults with FASD, biological mothers, other relatives, and health care providers. In addition, three one-on-one interviews were completed. Responses were coded into themes by two independent raters.

**Results:** Analyses yielded themes that distinguished between stigmatizing perceptions of children with FASD (e.g., immature, lazy, violent, socially inept) and biological mothers (e.g. child abusers, in denial, secretive, ignorant). Discrimination perpetuated by health care providers undermined services received by biological mothers and their children with FASD (e.g., lack of understanding, lack of identification, poor communication skills). Lastly, discriminatory behaviors specific to children with FASD and their biological mothers were identified (e.g., neglect, avoidance, abuse).

**Conclusion:** Results described the stigma experienced by different stakeholders related to FASD by identifying specific candidates for stereotypes, prejudice, and discrimination. These findings can be used to inform further assessment of stigma and also the development of tailored anti-stigma interventions.

### ARTICLE HISTORY

Received 24 February 2018

Revised 15 May 2018

Accepted 16 May 2018

### KEYWORDS

Stigma; FASD; fetal alcohol syndrome; stereotypes; prejudice; discrimination

A recent report of the National Academy of Science (National Academy of Sciences 2016), concluded that health decisions and life opportunities of people with behavioral health challenges – i.e., mental illness and/or substance use disorders – are greatly restricted by the stigma of these conditions. Stigma is a socially created construct that discredits people identified by specific marks (Goffman 1963). Stigma has been distinguished into public stigma (the prejudice and discrimination that harms a labeled group when the general population endorses stigma about that group) and self-stigma (the harm to self-esteem and self-efficacy when stigmas are internalized (Corrigan and Kosyluk 2014)). While marks like skin color lead to racism, marks for health conditions are typically diagnostic labels. Stigma dissuades people from engaging in treatment in order to avoid hurtful labels (for example, that person coming out of the clinic must be an addict) (Clement et al. 2015). It also robs people of rightful opportunities in work and independent living (Penn and Wykes 2003).

Typically, stigma is understood in terms of its harmful effects on the person with a labeled condition. For example, research would examine the stigma experienced by children with Fetal Alcohol Spectrum Disorder (FASD). FASD is a condition afflicting children born to women who consumed

alcohol during pregnancy and may include structural brain damage that leads to significant cognitive and social disabilities (Jones and Smith 1973; Riley et al. 2011). The focus here is the mother of a biological child with FASD and the degree to which she would be stigmatized for consuming alcohol while pregnant. Research has begun to examine stigma experienced by children and their biological mothers. A one-year media analysis showed two themes reflecting FASD stigma: sympathy for the child and disdain for the biological mother (Eguigaray et al. 2016). A qualitative study of interviews from biological mothers uncovered themes like mothers are bad, FASD occurs because of poverty, and recovery is insurmountable (Jacobs and Jacobs 2014). A recent quantitative study echoed the harm of stigma against biological mothers. It showed that biological mothers were viewed more negatively than women with mental illness, substance use disorders, or recent incarceration (Corrigan et al. 2017). Despite this beginning, there is still a need for developmental research on the stigma of FASD.

A methodological paper that emerged out of the NAS report outlined necessary steps in research programs seeking to describe stigma of specific behavioral health conditions (Corrigan, 2018). According to this paper, research needs to be anchored in a generic framework that described

constructs of stigma commonly experienced by people with different labels. The matrix in [Table 1](#), for example, describes three social psychological constructs that comprise public stigma experienced by all marginalized groups; e.g., people of color, women, elders, minorities in sexual orientation, or people with HIV-AIDS. [Table 1](#) illustrates these constructs in terms of mental illness (Corrigan and Kosyluk 2014). Stereotypes are overgeneralizations about a group (“People with mental illness are dangerous”). Prejudice is agreement with those beliefs that leads to emotional reaction (“Jim is mentally ill; I’m afraid of him”). Discrimination happens when unfair behavior is directed towards the individual or group (neighbors avoid talking to Jim). Discriminatory practices such as segregation, coercion, and avoidance can be damaging in the context of employment, housing and interpersonal relationships (Arboleda-Flórez and Sartorius 2008). Especially harmful discrimination has been demonstrated by health care providers; namely, their withholding health care because the labeled person somehow does not deserve it (Mittal et al. 2014). For example, research shows physicians offer a substandard of care to people labeled “mentally ill” (Druss et al. 2000; Sullivan et al. 2006; Koroukian et al. 2012).

Mixed methods research is needed to identify and cross-validate stereotypes, prejudice, and discrimination specific to labeled conditions. All facets of this research needs to be driven by Community Based Participatory Research (CBPR). Research about a social construct that impacts a community needs to be led by people from that community: people with FASD, biological mothers, other relatives, and service providers (Minkler and Wallerstein 2008). Hence, members of the CBPR team are not the object of the study but rather a partnership of individuals conducting the research. The CBPR team’s first step is to conduct qualitative research to identify candidates for stereotypes, prejudice, and discrimination of the targeted group and condition. Subsequent quantitative research cross-validates these findings (Corrigan, 2018).

In this paper, we review qualitative findings from focus groups led by a CBPR team of stakeholders related to FASD. By stakeholders we mean the mothers who drank alcohol while pregnant, their children with FASD, other concerned family members such as husbands or foster parents, and health care providers. The team sought to understand stereotypes, prejudices, and discrimination separately for children with FASD and for their biological mothers. Given research about the inverse relationship between stigma and the provision of health care (Mittal et al. 2014), the CBPR team was especially concerned about the impact of stereotypes and prejudice on services provided by pediatric and obstetric health care providers. Hence, the CBPR team conducted focus groups on stakeholders to identify candidates for stereotypes, prejudice, and discrimination related to FASD.

**Table 1.** Social Psychological Constructs that Describe the Public Stigma of Mental Illness.

Stereotype (cognitive)	People with mental illness are incompetent.
Prejudice (affective)	Landlord mistrusts ability of person with mental illness to pay rent.
Discrimination (behavioral)	Landlord won’t rent apartment.

## Methods

A CBPR team of 9 members was convened over a year to address the priorities of this study: (1) identify the stereotypes and prejudice of children with FASD and biological mothers; and (2) identify the discrimination that hamper these two groups, especially in the health care setting. The group included two biological mothers of children with FASD, one adult with FASD, one adoptive mother, a researcher, and four healthcare providers (two from pediatrics and two from obstetrics). Two of the healthcare providers were male; all other participants were female. As per expert recommendations, CBPR teams are kept between 8 to 10 people (Minkler and Wallerstein 2008) to make sure participants fully engage over the course of any project. The team’s first task was to come to some overall consensus about the stigma of children with FASD and their biological mothers. They used this consensus to generate an interview guide for focus groups or one-on-one of key stakeholders. The interview guide began with an overview question: “How do you describe fetal alcohol spectrum syndrome to other people?” The guide then transitioned to questions about participant attitudes, ideas, and beliefs about children with FASD and their biological mothers. Then, focus group members or individual interviewees were asked about how doctors, “meaning specifically pediatricians or obstetricians,” impact children with FASD and/or their biological mothers.

The CBPR team also addressed group logistics such as how many groups should be conducted? How should stakeholders be recruited for the groups? Should groups be heterogeneous or homogeneous? The CBPR team decided to purposively recruit five types of people: adults with FASD, biological mothers of children with FASD, other relatives of children with FASD (including adoptive parents and/or siblings), pediatric health providers, and obstetrical health providers. The groups were homogeneous and limited to people with lived experience of the condition or service providers. Four focus groups of ninety minutes each were conducted between March and July of 2017. Demographics of the 20 focus group participants plus three individual interviewees are summarized in [Table 2](#). The sample was 70.0% female and 73.9% white. We were unable to recruit obstetrical health providers for focus groups and so their data was collected in one-on-one

**Table 2.** Demographics of participants.

Demographics	<i>n</i>
Stakeholder interest	
Person with FASD	1
Biological mothers	4
Other relatives	11
Healthcare providers	7
Gender	
Female	16
Male	7
Ethnicity	
White	17
African American	2
Asian American	1
Latinx	3
Age	
26–35	2
36–45	3
46–55	12
56–65	6

key informant interviews. Three providers responded: one obstetrician and two labor and delivery nurses. They were all female and all white. All aspects of the study were fully reviewed by IRBs at participating organizations. Participants were fully informed to the purpose of the study and signed their agreement to participate.

### Data analysis section

Responses were bulleted by a scribe during the interviews and transcribed into single manuscripts for coding. All original transcripts have been uploaded to OSF ([https://osf.io/be8qf/?view\\_only=87c7f776a6154a5a8206d4be754738cd](https://osf.io/be8qf/?view_only=87c7f776a6154a5a8206d4be754738cd)). Analyses revealed 377 independent items relating to stigma. Of these, 237 items described stereotypes and prejudice, and 140 items described discrimination. Overlapping items were redacted and similar items combined. Two independent raters sorted items into themes; after training, raters showed good inter-rater reliability ( $\kappa = 0.92$ ). These were reviewed by the CBPR team resulting in changes including recoding names and recategorizing items.

### Results

Focus group analyses yielded themes that distinguish stereotypes about children with FASD ( $n = 11$  themes) from stereotypes about biological mothers ( $n = 12$  themes). These are summarized in Table 3. Analyses also distinguished prejudices towards children from those towards biological mothers. Seven themes describe discrimination of the health care system towards those labeled with FASD (children or biological mothers). In addition, findings outlined themes that described discrimination specific to children with FASD and to biological mothers.

### Stereotypes

**Children with FASD.** Themes described several stereotypes that the public may hold about children with FASD. Most broadly, children were viewed as **different** compared to same age peers. They have different interests and should be defined by differing expectations. Research shows difference leads to disdain (Corrigan et al. 2017). Several stereotypes reflected negative developmental expectations about FASD. Children were re viewed as **brain disordered**. With brain disorder comes a mark of being damaged. Although participants admitted “retard” is a disrespectful term, they viewed children with FASD as **retarded**. They are **immature**: socially and behaviorally they do not act their age. “I have a sixteen year old that acts as a two year old.” One participant said she knew a woman “who might be dating at 18, but have a 15 year old mind set.” With brain disordered stereotypes came beliefs regarding **bad prognosis**. Participants believed the harm of FASD is for life, that “only the worst is in store.” Children with FASD are cursed with a hopeless life. They are nothing but a burden.

Children with FASD were viewed as **lazy**. They worked below their level of competence because they were not

**Table 3.** Stereotypes about FASD.

#### Stereotypes about Children with FASD

1. Different than normal people
  - They are a little bit different
  - We can't expect the same as other kids
  - They do not have the same interest.
  - They get more attention because of their differences.
2. They are brain disordered.
  - Part of her brain hurts.
  - Needs a second brain.
  - His brain doesn't work the same as others.
3. Retard
  - I don't like the word retard but she does have a disability.
  - Until three years, she couldn't talk.
  - Only weighed one pound when was born.
  - The word retard was used when I was growing up but it has changed a bit.
  - Some of the adults I heard in my generation used this term.
4. Immature
  - Socially and behaviorally do not act their age.
  - I have a sixteen year old that can act like a 2 year old.
  - He's very immature.
  - I see her dating maybe at 18 but will have a 15 year old mindset.
5. Bad prognosis
  - Permanent damage.
  - This is for life.
  - We assume the worst is going to happen with this kid.
6. Lazy
  - Unmotivated
  - They are lazy.
  - So then she was looked at as lazy.
7. Violent
  - Yells
  - Screams.
  - Bites.
  - Out of control.
  - Bad.
  - Irritable.
  - Hyper.
8. Difficulties with attention
  - Attention is a big concern.
  - One second they are doing something and then it can go off.
  - Within short span, jump around conversations.
  - Can't pay attention in school.
9. Difficulties with learning
  - Teaching them can be hard because they do not understand.
  - They have a lot of processing issues.
  - Slow.
  - Learning problems.
  - They don't understand.
10. Difficulty forming social relationships
  - He wants to connect but does not know how.
  - He doesn't understand social cues.
  - He defiantly avoids social interactions.
  - In social activities, she can look snobby.
11. Facial abnormalities
  - Strange facial features.
  - Looks different.
  - Doesn't Smile

#### Stereotypes about Biological Mothers of Children with FASD

1. Bad child abuser
  - It's a form of child abuse.
  - Evil.
  - Bad people do this.
  - People say they are bad mothers.
  - They are selfish.
  - They put their needs, wants, desires ahead of their child.
2. Don't care
  - Mom did not take care of child.
  - No conscience.
  - Lack empathy.
3. In denial
  - They give excuses.
  - In denial.
  - Mom says. “I just do what everyone else does.”

(continued)

Table 3. Continued

## Stereotypes about Children with FASD

4. Secretive
  - They are shady.
  - Secretive.
  - You really have to investigate their past.
5. Guilty
  - Mom's guilt is huge.
  - They could be feeling guilty.
  - Guilt; shame on me.
6. Ignorant
  - Maybe she did it by mistake because she was ignorant.
  - They think a little alcohol is okay.
  - Moms have a lack of knowledge.
  - They are uneducated.
  - How could you, in this day and age, not know alcohol is bad during pregnancy?
  - We want to ask the parent, "don't you understand what you did by drinking?"
7. Addicts
  - Alcohol has control of her mind.
  - I'm a drug addict.
  - They still have drug and alcohol problems.
  - They just cannot stop.
8. History of maltreatment
  - Many times the mothers had a tough life of domestic violence and sexual abuse.
  - She wasn't treated well.
  - She had a bad childhood: foster child, sexual abuse, alcoholic parents).
9. Poor social connections
  - Not much of a social network.
  - Social problems.
  - Relationship problems.
10. Socioeconomic status
  - Lower income.
  - Difficult socio-economic status.
  - Poor.
  - Tons of drinking in upper middle class.
  - Blasted by 10AM at the pool.
11. Bad prognosis
  - They might do something that is even higher risk.
  - Could put the child at risk again due to poor judgment in the past.
  - They keep having babies.
  - They could do it again.
  - The FASD mom would be in a higher risk category for me.
12. They deserve harsh judgment
  - I stopped giving them the benefit of the doubt.
  - They did something wrong or terrible. They deserve stigma.
  - Hard not to stigmatize them because they are doing something that harms their baby.

motivated. They were also stereotyped as **violent**. They are wild; children with FASD are irritable, out of control, yelling, and biting. They have stereotypic cognitive deficits. They **can't pay attention**. They have a short span often jumping around from topic to topic in social situations. They also are **unable to learn** because they have processing issues. They were viewed as slow. FASD also causes children to have **difficulty with social relationships**. They do not know how to connect with others, frequently missing social cues. In fact, they cause family break-ups. Finally, children with FASD have **facial abnormalities**. They do not smile much and look obviously different than most everyone else.

**Biological mothers of children with FASD.** Research participants provided themes that corresponded with 12 stereotypes about biological mothers. Biological mothers were viewed as **child abusers**. Consuming alcohol while pregnant is "evil" and "a form of child abuse." They are self-centered. Biological mothers put their needs ahead of their child; they are not worthy of motherhood. As a result, biological

mothers **don't care** about their child. They have no conscience and lack empathy. Biological mothers are **in denial**. They give excuses for alcohol consumption while pregnant or say "their behavior was not different from the norm." They are **secretive** and **guilty**. They are ashamed of what they did and try to keep it hidden from others. FASD occurred because biological mothers are **ignorant**. They failed to understand the harmful effects of alcohol consumption during pregnancy.

Biological mothers are viewed as **addicts**. Alcohol had "control of their mind" such that they were "unable to stop." They are partiers and losers. Addicts have history of **maltreatment**. Biological mothers are often thought to have been victims of domestic violence or sexual abuse. They are believed to have had "bad childhoods," perhaps as "foster children," abused by their parents. In some way, they are continuing the pattern of maltreatment. As a result, biological mothers have **poor social connections**. They have relationship problems and few social supports on which they might rely. Similarly, biological mothers are stereotyped as being from a **skewed socioeconomic status**. FASD is a problem of the poor class and people of color. Outcome is viewed negatively. **Bad prognosis** is the expectation not recovery. The public believes mothers are likely to do it again. As a result, biological mothers **deserve harsh judgments**. "They did something terrible – they harmed their baby – and therefore deserve the stigma."

### Prejudice

Typically, focus groups generate a rich list of stereotypes about a group but, prejudices, the emotional reactions, are usually narrower (Corrigan, 2018). Research participants in this study identified three emotional reactions to the stereotypes of biological mothers. The public viewed them with **anger**. "Pregnancy and drinking makes me furious." Research participants recall specific harmful situations with concern. "It's hard because we had to change the name of my brother; that obviously upsets me." "I am raising someone else's kids with FASD so I get angry." With anger comes **disapproval**. Research participants said any substance in the body during pregnancy is not okay. "Moms have no right to bring children into the world like this." Interestingly, research participants also reported **sympathy**. They specifically report pity believing that biological mothers were victimized by their own abusive parents or by the unfortunate circumstances of their SES. No clear prejudicial affect about children with FASD emerged.

### Discrimination

Discriminatory behaviors that result from endorsing stereotypes and reacting emotionally were ordered into those that come from health care providers and those directed to children with FASD or to their biological mothers. These are summarized in Table 4.

**Health care provider discrimination.** Seven sets of discriminatory behaviors were identified by focus group



**Table 4.** Discrimination that results from stereotypes and prejudice about FASD.

In Health Care
<ol style="list-style-type: none"> <li>Fail to be educated <ul style="list-style-type: none"> <li>I wasn't trained that way.</li> <li>FASD information in medical school is only small portion of training.</li> <li>Twenty years ago, doctors did not learn anything about it.</li> <li>Doctors have no experience with FASD in their training.</li> <li>In affluent areas, pediatricians do not see a lot of adopted kids.</li> <li>Alcohol used to be prescribed during pregnancy for high blood pressure.</li> </ul> </li> <li>Fail to understand FASD <ul style="list-style-type: none"> <li>Unaware of FASD in doctor's patient load</li> <li>We don't want to think about FASD in our world.</li> <li>They don't understand the neurodevelopmental consequences.</li> <li>It's not talked about among colleagues.</li> </ul> </li> <li>Poor identification of child with FASD <ul style="list-style-type: none"> <li>We don't look for the diagnosis.</li> <li>I don't see anything dysmorphic. I don't think about it at all.</li> <li>It's not high on my diagnostic radar.</li> <li>There are many kids with FASD that are not being recognized.</li> <li>Don't realize how much FASD could potentially pass through the office.</li> <li>So focused on drug use, they don't ask about alcohol.</li> </ul> </li> <li>Inadequate treatment (including early intervention) <ul style="list-style-type: none"> <li>Doctors don't know what to do.</li> <li>They think kids will grow out of it.</li> <li>Let's give the child a month and see if they catch up.</li> <li>Just call child protective services.</li> <li>Why are they delaying all the time?</li> </ul> </li> <li>Fail to referral <ul style="list-style-type: none"> <li>Doctors don't send them to the right doctor for diagnosis.</li> <li>The provider has to be beat over the head to give a referral.</li> <li>Not referring right away.</li> </ul> </li> <li>Poor communication skills <ul style="list-style-type: none"> <li>Dismissive pediatricians.</li> <li>They don't talk to you about it.</li> <li>Doctors get very fire and brimstone.</li> <li>Fail to reflective listen.</li> <li>Pediatricians focus on the baby only. They fail to discuss concerns of the mom.</li> <li>Passive doctors.</li> </ul> </li> <li>Fear of assertive messages to mother <ul style="list-style-type: none"> <li>Doctors are apprehensive to confront mother about behavior.</li> <li>They don't want to feel like they are accusing the parent.</li> <li>If we offend them, they won't come back to see us.</li> <li>Mom will get angry with me.</li> <li>I could get a negative patient satisfaction survey.</li> <li>I don't want to make them feel guilty.</li> </ul> </li> </ol>
All Other
<b>AGAINST CHILDREN WITH FASD</b> <ol style="list-style-type: none"> <li>Abuse <ul style="list-style-type: none"> <li>Abuse from other parent such as biological father because he didn't understand.</li> </ul> </li> <li>Social exclusion <ul style="list-style-type: none"> <li>She's not included.</li> <li>Off the field, she does not hear from the team.</li> <li>I got locked in room; bullied.</li> </ul> </li> <li>Disrespect <ul style="list-style-type: none"> <li>Jokes on TV.</li> </ul> </li> <li>Structural discrimination <ul style="list-style-type: none"> <li>There are other diagnoses – e.g., ADHD – that yield better services.</li> <li>Schools aren't set up for FASD children.</li> </ul> </li> </ol> <b>AGAINST BIOLOGICAL MOTHERS OF CHILDREN WITH FASD</b> <ol style="list-style-type: none"> <li>Potential violence <ul style="list-style-type: none"> <li>I can't be with biological moms. If you put me with them, I would become violent.</li> </ul> </li> <li>Avoidance <ul style="list-style-type: none"> <li>I would only go to support groups that did not have bio moms.</li> </ul> </li> <li>Deny rights <ul style="list-style-type: none"> <li>Two police just came in and said we are taking your baby; just standing there with their guns out.</li> <li>I told them I was pregnant and want to get clean and they said to get me out of there.</li> </ul> </li> </ol>

members and are listed in Table 4. Many providers **fail to be educated** about FASD. Neither pre-service nor in-service training provides up-to-date information about FASD and corresponding evidence-based practices. Even more, many

health care providers have no interest in learning more about this topic. As a result, health care providers fail to **understand FASD**. They have insufficient information about the harmful effects of alcohol consumption during pregnancy. They are ill-prepared to guide pregnant women, and mothers with children manifesting FASD soon after birth. They also don't prioritize this kind of diagnosis as important in children's health. Hence, as public health agents, many providers are **unable to identify children with FASD**. Health providers said FASD was "not high on their diagnostic radar." They fail to identify dysmorphic features. As a result, **treatment is inadequate**. Poor identification delays early intervention. Some providers believe "children will grow out of it." Many physicians just "do not know what to do." Compounding inadequate treatment are **insufficient referrals**. Providers do not understand specialists who can address the needs of the child or mother. Sometimes, they react slowly, not referring soon after the condition emerges.

Compounding poor intervention is the nature of patient-provider interactions. Some providers **lack communication skills** that facilitate treatment. Some are dismissive of mothers, reacting to them with "fire and brimstone." Some providers focus only on the baby, ignoring the "mother in the room." They have not mastered the kind of reflective listening essential to hearing the mother's concerns. Many providers are just uncomfortable discussing the topic. Interestingly, other providers exacerbate the patient-provider relationship when they are **not appropriately assertive to the mother**. Some providers report not wanting to "accuse the patient." They are concerned that if they confront the biological mother, she will not return. "Mom's will get angry with me if I push."

**Discrimination against children with FASD.** Table 4 lists four sets of discriminatory behaviors the public aims towards children. First is a general sense of **abuse**. For example, a biological father might physically abuse the child with FASD because he does not understand the social challenges that accompany the disability. Sometimes they are over-medicated in order to control them. More frequently, children with FASD experience **social exclusion**. Research participants reported that children with FASD were often excluded from school events or sports teams. Sometimes, these children are bullied. Other times, they are outright ignored. More broadly, exclusion corresponds with general **disrespect**. Research participants recounted skits on TV that make fun of the child with FASD. Adults with FASD are treated like children. Finally, there is **structural discrimination** that undermines the opportunities of children with FASD. For example, government services are sometimes set up to serve children with diagnoses other than FASD, such as ADHD. Some schools are not organized to provide ample services to children with FASD.

**Discrimination against biological mothers.** Table 4 provides three discriminatory behaviors directed against biological mothers. Like the child, some mothers experience abuse or **direct violence**. One participant said, "I can't be with moms. If you put me with them, I would hurt them." **Avoidance** occurs. One individual refused to participate in support groups that had biological mothers. Biological

mothers are often excluded from social gatherings. **Rights are denied.** One biological mother recounted how police officers entered her delivery room with guns drawn saying they were “taking her baby.” Another recounted a health exam where the woman told the doctor “I’m pregnant and want to get clean.” “They said to get me out of there.”

## Discussion

Qualitative themes of stigma portrayed here represent the experiences of people closest to the issue. Taken together, these findings map onto the generic model of stigma in [Table 1](#). Participants shared examples of public stigma including stereotypes, prejudice and discrimination related to FASD. Stereotypes differed depending on whether the object was the child with FASD or the biological mother. Children were stereotyped as, among other things: different from the norm, brain disordered, immature, lazy, violent, with difficulties related to attention, learning, and social relationships. Biological mothers were viewed as being child abusers who do not care about their children, in denial, secretive, ignorant, addicted, with a history of maltreatment, from a low SES, poor social connections, and deserving harsh treatment.

Stereotypes endorsed by the public become prejudice and lead to emotional reactions. Interestingly, research participants were only able to elucidate prejudicial affect against biological mothers. Emotions were mixed: on one hand, they included anger and disapproval, but on the other hand, they also included sympathy.

Discrimination perpetuated by health care providers undermined services received by biological mothers and their children with FASD. Specific discriminatory behaviors in the health sector included providers who lack education about FASD. Hence, they neither understand the syndrome, nor are able to identify children with the disorder. As a result, they provide inadequate treatment, especially by not helping patients make appointments with providers who are skilled in appropriate evidence-based practices. They also lack the kind of communications skills that help mothers fully engage in care. In addition, discriminatory behaviors were identified specific to children with FASD and biological mothers. Children were sometimes physical abused, socially excluded, and disrespected. In addition, structural discrimination undermines children’s opportunities when service systems or schools, for example, are unable to develop service plans specific to the challenges of FASD. Biological mothers also are the victims of physical abuse and avoidance. They may have their parental rights unduly curtailed.

An interesting question is whether stereotypes and discrimination like these might be in some ways justified. Called “kernel of truth”, social psychologists have wondered whether some stereotypes are accurate and therefore valid ([Campbell 1967](#); [Vinacke 1949](#); [Allport 1954](#)). Assertion like the stereotype that “all Irish are drunks” rests on presumed higher rates of alcohol consumption among Irish citizens. Hence, the stereotype that all biological mothers of children with FASD are “child abusers who were victims of maltreatment themselves” is thought to reflect findings from population research. In fact, research has failed to support

assumptions about kernel of truth: Blacks are not more violent, Asians are not better mathematicians, and women are not less intelligent ([Jost and Banaji 1994](#)). In fact, just repeating these stereotypes shows the slippery slope provided by kernel of truth. No proponent of social justice wants to defend generalized negative assertions about any ethnic group. But what about stereotypes that children with FASD have attention, cognitive, and social difficulties? Isn’t that true because it is inherent to the diagnosis? Readers need to discern the purpose of diagnostic criteria and the effects of stereotypes. The former are meant to guide providers and their patients in understanding the presenting syndrome that may challenge their health. They are potent to the extent that they inform effective intervention plans. Stereotypes are expectations of the group and the harm is in extending the possibility of an individual trait to the entire group. Just because a child is labeled with FASD does not necessarily mean they will be socially inept. Just because a biological mother is labeled as someone who consumed alcohol while pregnant does not mean she wanted to abuse her child. Hence, kernel of truth can be a treacherous criterion for judging harmful beliefs.

These qualitative findings are first steps in a mixed methods program meant to describe the stigma experienced by different stakeholders related to FASD. Findings herein suggest candidates for the stereotypes, prejudice, and discrimination that harm children with FASD and biological mothers. The next step is a quantitative study that cross-validates qualitative candidates outlined herein ([Corrigan, 2018](#)). A larger sample provides feedback on the relevance and importance of stigma items that emerged in [Tables 3 and 4](#). The factor structure of validated items can then be determined to uncover hierarchical factors to which individual stereotypes, prejudices, and discrimination might be directed.

There are limitations to these findings that need to be considered in research separate from the cross-validation studies. Sample size was in the range of many qualitative studies but is often judged in terms of saturation; were all themes generated by those who participated in these groups or key interviews? Subsequent research needs to determine whether additional candidates for stereotypes, prejudice, and discrimination emerge. Note that candidates for prejudicial affect were far fewer than the other two categories. Although this is often the case in stigma development work ([Corrigan, 2018](#)), future studies need to better consider questions in the interview guide that query for emotions more thoroughly. Discriminatory behaviors included a large and important set of candidates related to provider behavior. Future research should consider interview guide queries that examine discrimination in other settings; e.g., school systems poorly set up to address the needs of children with FASD or extended family who exclude biological mothers. The objects of stigma in this study were children with FASD and biological mothers. Subsequent studies might want to consider other stakeholder groups such as parents who adopt children with FASD or other biological relatives such as siblings of people with FASD. These studies might also want to broaden the arena of other professional stakeholders including those from social service and education. Finally, this study was limited to

understanding the public stigma of mental illness. Future research should attempt to make sense of self-stigma; i.e., the degree to which biological mothers internalize these stereotypes harming their sense of self-worth or self-efficacy. In fact, an equally important agenda would be to examine public and self-stigma in people with FASD.

Results from studies like these may yield two benefits when validated by subsequent quantitative work. First, they inform assessment programs that seek to understand the depth and breadth of stigma about different FASD stakeholders. Findings summarized in [Tables 3](#) and [4](#) begin to describe stigma and its egregious effects. They may lead to assessment strategies that provide indices of stigma in a targeted group. Additional research might also show whether and how the stigma of health care providers undermines their diagnosis of FASD in children (Mukherjee et al. 2015).

Second, findings like these inform the development of anti-stigma programs. Development of programs like these need to be grounded in the already extensive body of research on stigma change. Two strategies for changing stigma related to behavioral health have emerged in the research literature: education and contact (National Academy of Sciences 2016). Education seeks to decrease stigma by contrasting the myths of mental illness (e.g., people with schizophrenia choose to be mentally ill) with facts (schizophrenia is genetic in origin; people do not choose to have this disorder). Contact decreases stigma by directly challenging individual prejudices against the group. Results of one meta-analysis show contact to have superior effects to education immediately after the intervention (Corrigan et al. 2012) and at follow-up (Corrigan et al. 2015). As applied to FASD stigma, contact includes on-the-way-down stories (the challenges of the health condition leading, for example, to a child with significant disabilities) and on-the-way-up stories (despite these challenges, mother and child have achieved aspirations) (Corrigan et al. 2013). Contact-based programs are most effective when they strategically target a group (Corrigan 2004). Targets might be, for example, pediatric providers who learn that biological mothers can be an essential partner in the child's treatment, or elementary school teachers who learn how to craft meaningful education programs.

Findings from studies like these suggest content for the targeted program led by people with lived experience. What unspoken stereotypes need to be challenged so the target group becomes more willing to relinquish stigma? Even more important is the behavior prescription that comes from an anti-stigma intervention. What action steps do advocates desire if stigma is diminished? Discriminatory behaviors like those in [Table 4](#) are useful here. Anti-stigma programs seeking to better engage pediatric providers might want to prescribe better communication skills for these providers or a list of referrals.

Finally, findings from research like this may inform programs that best engage biological mothers in services. Consistent with the literature, it seems that strategies that integrated substance use concerns with maternal parenting and child-care needs may best address the disabilities of FASD (Milligan et al. 2011; Espinet et al. 2016; Milligan et al. 2017).

## Conclusion

Stigma surrounding FASD is pervasive – it impacts individuals with FASD, their biological mothers, and health service providers. Analysis yielded qualitative themes that distinguished between stigmatizing perceptions of each of these groups by identifying specific candidates for stereotypes, prejudice, and discrimination. Themes highlighted the egregious effects of stigma including loss of opportunities, social exclusion, and inadequate treatment. Present results have the potential to inform improved assessment stigmatizing experiences and develop targeted anti-stigma interventions for FASD stakeholders. Future research should incorporate quantitative methods to cross-validate findings.

## Disclosure statement

No potential conflict of interest was reported by the authors.

## Funding

This work was supported by the Centers for Disease Control and Prevention (CDC) under Grant number NU01DD001144.

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