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## Towards a better understanding of the social stigma of facial difference

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## **Abstract**

Facial Difference (FD; i.e., the perception of a one's face as visibly different) encompasses a wide range of different conditions. Despite being primarily considered to be an individual issue, early scholars stressed the social dimension in FD. They showed that FD is actually a social stigma, which was reinforced by many research conducted afterwards. The aim of the present paper was thus to provide an overview of this research in light of the social stigma framework put forth by Pryor and Reeder (2011). While demonstrating that FD is a public stigma, a self-stigma, a stigma by association, and a structural stigma, this overview stresses the need for the development of interventions, and how the social stigma literature could be helpful for that purpose.

## **Keywords**

Facial difference, facial disfigurement, stigma.

## 1. Introduction

Researchers struggle to define Facial difference (FD). FD usually tends to be defined biomedically with emphasis placed on individual impairment (Katz et al., 2000; Krishna, 2009; Rakic et al., 2018). However, FD is not only an individual experience (Atkinson et al., 2020). Rather, how FD is viewed and perceived is inherently social, reflecting interactions between social norms and individual attitudes (Thompson & Kent, 2001). Therefore, we define FD as a face whose characteristics make it deviate significantly from what an individual who perceives it expects from a normal human face.

Often, but not always FD is stigmatized. Pescosolido and Martin (2015) define stigmatization as a socially and culturally constructed process where a person is labelled as different and then devalued, resulting in status loss and discrimination, and Phelan et al. (2008) claim that stigma serves three functions: 1) to keep people in via norm enforcement; 2) to keep people out through avoidance; and 3) to keep people down through domination and exploitation.

In this paper, we employ a widely used stigma framework, namely the social stigma framework put forth by Pryor and Reeder (2011; see Fig. 1; Bos et al., 2013), to unpack the stigma of FD. Pryor and Reeder's (2011) framework is, in our opinion, the most comprehensive framework for understanding stigma. It brings together the broad range of stigma forms (e.g., public stigma, perceived stigma, enacted stigma, anticipated stigma, internalized stigma, structural stigma, stigma-by-association) in a cohesive and theoretically sound framework, which has demonstrated utility across a number of stigmatized identities, conditions, and behaviors, including sexual orientation (i.e., being lesbian; Leonard, 2021), race and ethnicity (i.e., being Black; Pryor et al., 2012), marital status (i.e., being single; Ochnik & Mandal, 2016), adolescent motherhood (Bermea et al., 2018), weight (Pryor et al., 2012), sex trafficking (i.e., being a victim of sex trafficking; Basu, 2022), criminal offenders (Moore et al., 2016), noncommunicable neurological disease (Elliot et al., 2019), Autism Spectrum Disorders (Mazumder & Thompson-Hodgetts, 2019), Fetal Alcohol Spectrum Disorders (Roozen et al., 2022), HIV (Pryor & Reeder, 2011; Stutterheim et al., 2022; Van Der Kooij et al., 2021), menstruation (Coleman & Sredl, 2022), and mental illness (Shu et al., 2022; van der Sanden et al., 2015) including depression (Aziz &

Khan, 2021) and substance use dependence (Burgess et al., 2021). Our purpose is to discuss research on FD stigma in the context of Pryor and Reeder's (2011) social stigma framework, thereby delineating how the social environment poses challenges for people with FD, how FD stigma is coped with, and, importantly, what can be done to reduce FD stigma.

We acknowledge that FD is not always stigmatized, and that people living with FD do not necessarily experience social difficulties. Nevertheless, given evidence that FD stigma does occur, and in light of the negative consequences of stigma for social and psychological well-being, we feel that an exploration of the FD literature using the social stigma framework is important as it allows us to effectively ascertain avenues for future research and, more importantly, it enables us identify important strategies for reducing FD stigma.

## 2. Pryor and Reeder's social stigma framework

The social stigma framework put forth by Pryor and Reeder (2011) outlines four forms of stigma: Public stigma, self-stigma, stigma-by-association, and structural stigma (Fig. 1). Public stigma represents people's cognitive, affective, and behavioral reactions to people with a stigmatized condition, and manifests on an interpersonal level. Self-stigma is the anticipation and internalization of society's negative beliefs about the stigmatized condition, and occurs on an intrapersonal level. Stigma-by-association entails social and psychological reactions to people associated with a stigmatized person (e.g., family and friends) as well as the impact of being connected to a person with a stigmatized identity or condition, and can be considered analogous to Goffman's (1963) courtesy stigma. Lastly, structural stigma is the legitimization and perpetuation of stigma by society's institutions and ideological systems through, for example, policy and legislation. This form of stigma occurs on organizational, institutional, or societal levels. The four types of stigmas are interrelated with public stigma being at the core of the other forms of stigma.

In what follows, we discuss the literature on FD in the context of each of the four forms of stigma put forth by Pryor and Reeder (2011).

## 2.1. Public stigma

From a social psychological perspective, public stigma comprises cognitions, affects, and behaviors. Cognitive reactions often reflect stereotypes, affective responses demonstrate prejudice, and behavioral reactions to a stigmatized condition like FD manifests as discrimination (often also termed enacted stigma; Bos et al., 2013; Stutterheim & Ratcliffe, 2021). Because public stigma is the core form of stigma, this is where the majority of research on FD stigma occurs. Below, we outline the various cognitive, affective, and behavioral responses that occur in interactions with people with FD as reported in the literature. We then look specifically at ambivalent reactions and their implications.

### 2.1.1. Cognitive reactions

Research on cognitive reactions to people with FD has shown that people without FD hold stereotypical representations of people with FD, and that these manifest via attributions of less favorable characteristics to people with FD, resulting in an ‘anomalous-is-bad’ stereotype (Jamrozik et al., 2019; Stone & Wright, 2012; Workman et al., 2021). This bias is contrary to the ‘beauty is good’ bias (Dion et al., 1972), whereby attractive individuals are favored in terms of personality traits, as well as in life opportunities (Eagly et al., 1991; Fig. 1. Types of stigma adapted from Pryor and Reeder (2011). Klebl, Rhee, Greenaway, Luo, & Bastian, 2022). The ‘anomalous-is bad’ bias would therefore work in the same way as the ‘ugly-is-bad’ bias (Griffin & Langlois, 2006) but more dramatically.<sup>1</sup>

Accordingly, people with FD have been rated as having significantly less positive personality traits (e.g., conscientiousness, emotional stability), less positive internal attributes (e.g., intelligence,

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<sup>1</sup>However, considering FD as an issue of unattractiveness is not always informative for considering the difficulties faced by people with FD (Roberts & Shute, 2011; Stone & Potton, 2014). Moreover, considering FD as intrinsically rather than culturally unattractive is problematic (e.g., see the career of Winnie Harlow as a model while living with a vitiligo).

honesty), less positive social attributes (e.g., likability, school success), and as less attractive (Bull, 1979; Collett et al., 2013; Jamrozik et al., 2019; Masnari, Schiestl, Weibel, et al., 2013; Rankin & Borah, 2003; Stone & Wright, 2012). These attributions have been made both on an individual level and in a group context (Workman et al., 2021).

As with other disabilities, there seems to be a “spread” of FD to people’s identity (see Nario-Redmond, 2020) whereby FD is perceived as an essential element of the person explaining his or her other characteristics (e.g., “he/she is not self-confident probably because of her FD”; see also Rumsey & Harcourt, 2012). However, research has shown that people with FD are more negatively evaluated than other people with visible physical disabilities (Bogart et al., 2019; Stevenage & McKay, 1999; Stone & Wright, 2012).

In fact, some studies suggest that faces with FD are actually processed differently than faces without FD. For example, studies using eye-tracking have shown that visual attention is drawn to the part of the face where FD is apparent (for a review, see Asaad et al., 2020). At the same time, FD diverts attention away from internal facial features like the eyes, which plays an important role in social interactions (Rasset et al., 2022a). Clearly, FD affects the allocation of overt visual attention, and not only because of its saliency (Ackerman et al., 2009; Boutsen et al., 2018, 2021). In fact, research has shown that faces with FD are not better memorized; people tend to confuse different faces with FD with each other more than different faces without FD (Ackerman et al., 2009).

Differential attention to faces with FD has also been explored using neuroimaging techniques. In a study by Hartung et al. (2019), faces with FD evoked lower neural responses in the anterior cingulate and medio-prefrontal cortex. As these networks are important in social cognition, notably for inferring feelings and mental states, this particular way of processing faces with FD is likely to have implications for social interactions as well (e.g., dehumanization Harris & Fiske, 2006, 2007, 2009; Hartung et al., 2019; Workman et al., 2021). Additionally, research using event-related potentials (ERP) showed alterations in the configural processing of faces with FD (i.e., the default mode of processing for ‘normal’ faces) (Huffmeijer et al., 2018; Parsons et al., 2013).

### 2.1.2. Affective reactions

A general preference for people showing no FD appears to arise early in child development (Harper, 1999; Masnari, et al., 2013; Richardson, 1971; Sigelman et al., 1986). Even at an implicit level, research has shown that people are quicker to associate FD with negatively valenced words than with positively valenced ones (Grandfield et al., 2005 yet not replicated by Roberts et al., 2017; Hartung et al., 2019; Stone, 2022).

Beyond a global negativity towards people with FD (Madera, 2016), specific affective reactions to FD have also been documented, with the emotion of disgust drawing specific interest (e.g., Shanmugarajah et al., 2012). Indeed, research shows that FD elicits significant activations in the amygdala and anterior insula, both of which are regions that react to disgust-inducing stimuli (Krendl et al., 2006; Workman et al., 2021). Also, in a study by Ryan and colleagues (2012), participants were asked to touch props that had been allegedly used by someone either with a birthmark or an infectious disease, and the results showed similar levels of behavioral avoidance and disgust for both conditions.

From an evolutionary perspective, disgust serves the function of avoiding disease (Kurzban & Leary, 2001; Oaten et al., 2009). However, disgust is especially prone to false alarms, and is frequently instinctively activated in perceivers when faced with a stigmatized condition (Oaten et al., 2009). This suggests that FD is misinterpreted as a disease (Ackerman et al., 2009; Kurzban & Leary, 2001; Ryan et al., 2012; Shanmugarajah et al., 2012). However, disgust reactions to FD are not universal. Recent research shows that biases towards faces with a scar vary based on exposure to Western culture (Workman et al., 2022).

In addition to disgust, research has demonstrated that FD also elicits threat reactions. In Blascovich et al. (2001) study, participants interacting with a made-up confederate exhibiting a port wine stain had increased cardiovascular activity, which is consistent with a feeling of threat. Also, in a study by Jones and Stone (1995), participants reported more discomfort towards people with FD than towards people living with other physical disabilities.



Additional affective reactions have been demonstrated by Stone and Potton (2014). In their study, participants were asked to report their subjective emotional experience when shown faces that were attractive, unattractive, or presenting a FD. The results showed that, when high anonymity was guaranteed, participants reported more sorrow and curiosity, less positive and more negative emotions. Based on this, a six-dimension typology describing a wide array of possible affective states experienced by perceivers of people with FD emerged (Rasset et al., 2022b). The dimensions are surprise, anxiety and embarrassment, disgust, hostility, sympathy, and neutral affective states.

### 2.1.3. Behavioral reactions

There is significant literature showing that people with FD experience enacted stigma or discrimination (for reviews, see Macgregor, 1990; Rumsey & Harcourt, 2004; Thompson & Kent, 2001; Wali & Regmi, 2017) across the life course (Feragen & Borge, 2010; Holland et al., 2019; Lawrence et al., 2011; Magin et al., 2008; Masnari et al., 2012; Strauss et al., 2007; Strobel & Renner, 2016) with the most detrimental impacts occurring in formative periods of life (e.g., adolescence; Bogart, 2015; Crerand et al., 2020).

Discriminatory responses tend to reflect a lack of social tolerance (Lawrence et al., 2011) and can manifest as unfriendly behaviors, avoidance, and ostracism (Bogart et al., 2012; Bonanno & Choi, 2010; Ryan et al., 2012). Additionally, people with FD have reported staring and unsolicited attention as behavioral responses (Bogart et al., 2012; Bonanno & Choi, 2010; Halioua et al., 2017; Lawrence et al., 2006; Rossi et al., 2009; Strauss et al., 2007; Strobel & Renner, 2016; Threader & McCormack, 2016). Research shows that people with FD may not experience the “civil inattention” that others commonly experience (Macgregor, 1990), particularly when they are singled out (Kornhaber et al., 2014). Visible difference may also elicit questions, comments, and other privacy intrusions (Bogart et al., 2012; Bonanno & Choi, 2010; Rossi et al., 2009; Strauss et al., 2007).

Furthermore, people with FD experience social rejection, which can be subtle or blatant (Ginsburg & Link, 1993). In terms of hostile behaviors, people with FD have reported teasing as a

common experience, as well as harassment (Bogart, 2015; Bogart et al., 2012; Bonanno & Choi, 2010; Feragen & Borge, 2010; Griffiths et al., 2012; Halioua et al., 2017; Holland et al., 2019; Lawrence et al., 2011; Magin et al., 2008; Nishikura, 2009; Strauss et al., 2007; Turner et al., 1997; Visram et al., 2019). Teasing and, to a greater extent, bullying have a detrimental impact on psychological well-being, especially with regard to self-esteem, self-image, and self-consciousness, but also in terms of body image and satisfaction with facial appearance (Crerand et al., 2020; Feragen & Borge, 2010; Magin et al., 2008). It is also important to note that social interactions are not always antisocial; sympathetic reactions have also been reported, but these are sometimes considered stigmatizing, particularly when expressed in public, manifested as unsolicited help, or when they show pity (Bonanno & Choi, 2010).

The various behavioral reactions to people with FD occur across a number of contexts, both private (e.g., at the swimming pool, at the hairdresser's, on the street; Ginsburg & Link, 1993; Koster & Bergsma, 1990) and professional (e.g., at work; Porter et al., 1986; Stevenage & McKay, 1999; Stone & Wright, 2012a, 2013; Stone et al., 1992).

It is noteworthy that most of the literature on behavioral responses to people with FD focus on the experiences of people with FD, rather than on the behavior of people interacting with people with FD (i.e., the perceiver). However, there are a few experimental studies that have shown that FD affects recruitment decisions (e.g., intention to hire, especially for jobs with high levels of customer contact; Stevenage & McKay, 1999; Stone & Wright, 2013), interpersonal distance (Albrecht et al., 1982; Pausch et al., 2016), and willingness to help (Knapp-Oliver & Moyer, 2009). Also, there are a few behavioral studies that have provided evidence that discrimination does occur (e.g., aversion to interaction, avoidance). Notably, Houston and Bull (1994) demonstrated that people avoided sitting next to a person with a FD, and Rumsey et al., (1982) showed that people stood significantly further away from people with FD on the streets of London. Both real-life and laboratory setting results consistently show that FD elicits avoidance behaviors (Miller & Maner, 2011).

In order to synthesize the stigma experiences of people with FD, Partridge (1998) developed, based on testimonies and his own experience of FD, the acronym "SCARED" (Fig. 2) which summarizes

the various cognitive, affective, and behavioral reactions experienced by people with FD, and also refers to the uncertainty and fear felt in a social situation between two people where one has FD.

#### 2.1.4. Ambivalent reactions

Stigmatized conditions like FD do not only evoke negative reactions. They also, like other stigmatized conditions, elicit ambivalent reactions (e.g., mixed affective reactions ranging from sympathy to hostility). This can be explained by the dual-process model of stigmatization (Pryor et al., 2004) which postulates that reactions to people with a stigmatized identity or condition rely on two processes, namely a 'reflexive system' and a 'rule-based system'. The former engenders automatic and immediate responses which can then be counterbalanced by a more controlled and thoughtful reaction, which occurs slightly later. For this reason, reactions to people with FD often comprise a mixture of negative and positive feelings (Dovidio et al., 2000; Rasset et al., 2022a, 2022b).

Ambivalence can lead to nervousness caused by pressures to express kindness and compassion, while actually feeling anxious and uncomfortable (Dey et al., 2015). Further, with the knowledge that people should not judge based on appearance, people interacting with someone with FD may attempt to compensate by displaying more controlled sympathetic behaviors and willingness to help (Nario-Redmond et al., 2019) but not fully succeed leading to awkward interactions (Hebl et al., 2000). For example, Rumsey et al.'s (1982) on how FD impacts proxemic behavior in the street was not replicated twenty years later in Australia by Roberts and Gierasch (2013). This may be because stigma towards people with FD has evolved into something less overt.

This contention is further supported by Knapp-Oliver and Moyer's (2009) work showing that discrimination against people with FD may be stronger when the context allows the stigmatization to be subtle. Indeed, as normative pressures increasingly encourage people to be kind to people with disabilities (Nario-Redmond et al., 2019), self-presentation biases are likely to occur, and this is reinforced by research showing that negative emotions were only reported when anonymity was guaranteed (Stone & Potton, 2014; see also Jewett et al., 2018).

To further explore this ambivalence, researchers have ingeniously employed methodologies that reach beyond the explicit measurement of stigmatizing reactions (e.g., self-reported questionnaires such as the Measure of Disease-Related Stigma; Stump et al., 2016) to include more implicit measures (e.g., Implicit Association Test; Grandfield et al., 2005; Stone & Wright, 2012). Also, physiological measures have been helpful in establishing affective reactions (Blascovich et al., 2001) and circumventing social desirability bias. These include eye-tracking measures for gaze behavior (see Asaad et al., 2020; Rasset et al., 2022a, 2022b), and fMRI for cognitive processes and their neural correlates (e.g., Hartung et al., 2019; Krendl et al., 2013).

#### 2.1.5. Summary

Evidently, there is abundant research showing that public stigma in the form of cognitive, affective, and behavioral reactions, occurs and impacts the lives of people with FD. Some of this research, predominantly research on cognitive and affective responses, focuses on the perspectives of ‘perceivers’ thus those without FD that engage with some with FD. Other research, particularly research focusing on behavioral responses to FD, hones in on the lived experiences of people with FD across various contexts. Ambivalent reactions to people with FD are also present, demonstrating that stigma is often subtle. Also, it is interesting to note that, although researchers often focus on one type of FD (e.g., clefts), reactions of perceivers to different FD are often very similar. This suggests that we should be studying reactions to various FD in a unitary manner.

## 2.2. Self-stigma

Self-stigma entails the anticipation of stigma (i.e., anticipated stigma) and the internalization of the negative beliefs about people with FD reflected in public stigma, (i.e., internalized stigma; Pryor & Reeder, 2011; Bos et al., 2013). The experience of self-stigma is prevalent and widespread among people with FD (for reviews, see (Dimitrov & Szepietowski, 2017; Germain et al., 2021; Reynolds & Harris, 2021), as is also reflected in the development and validation of standardized scales for

measuring self-stigma, such as the Feelings of Stigmatization Questionnaire (Ginsburg & Link, 1989), the Questionnaire on Experience with Skin Complaints (Schmid-Ott et al., 1996), and the Shame and Stigma Scale (Kissane et al., 2013).

Various manifestations of self-stigma have been reported, including the anticipation of rejection, feelings of being flawed, sensitivity to the opinions of others, feelings of guilt and shame, and feeling the need to be discrete about one's FD (Ginsburg & Link, 1989). These manifestations of self-stigma lead to fear of negative evaluations, fear of intrusive behaviors and even fear of provoking disgust in others, which, in turn, can lead people to conceal their FD when possible (Clarke et al., 2014; Keys et al., 2021; Leary et al., 1998; Reynolds & Harris, 2021; Sharratt et al., 2020; Tiemens et al., 2013).

People with FD also internalize negativity and have reported considering themselves to be dirty, ugly, or flawed (Bradbury, 2012; Brown et al., 2008; Crerand et al., 2020; Halioua et al., 2017; Lanigan & Cotterill, 1989; Visram et al., 2019). Accordingly, there has been substantial research attention to the role of shame in appearance related issues (for a review, see Halioua et al., 2017; Keys et al., 2021; Kissane et al., 2013; Rumsey & Harcourt, 2005). For some conditions, such as head and neck cancers that are related to lifestyle risk factors (e.g., tobacco use; Threader & McCormack, 2016), shame is amplified by perceptions that one may be responsible for one's FD (Goyal et al., 2021; Kissane et al., 2013).

Research has consistently demonstrated that enacted stigma (e.g., bullying) can lead to felt stigma (e.g., fear of rejection) and internalized stigma (e.g., feeling unattractive; Griffiths et al., 2012). For instance, in a qualitative study conducted with adolescents with cutaneous leishmaniasis, the reactions of others were related to subsequent lower self-concept (Bennis et al., 2017). At the same time, anticipated stigma and internalized stigma can occur even in the absence of enacted stigma, and research has indeed shown discrepancies between the perception that stigma is present and actual discrimination, also for FD (Kleck & Strenta, 1980). This is termed stigma consciousness (Pinel, 1999). Although stigma consciousness has been studied among people with physical disabilities (Kowalski &

Peipert, 2019), to our knowledge, to date, no studies have looked at stigma consciousness specifically among people with FD.

For FD, it is often difficult to disentangle the negative psychological and well-being impacts of stigma from the impact of impairment or trauma, which is notably present in individuals whose condition is acquired (Bogart, 2014). Nonetheless, self-stigma does have detrimental effects for the psychological and social well-being of people with FD. Self-stigma in general is associated with decreased hope, lower self-esteem, poorer self-efficacy, and reduced quality of life (see Mittal et al., 2012). Accordingly, people with FD may have decreased self-confidence, increased self-consciousness, and they may be dissatisfied with their facial appearance (Hunt et al., 2005; Sharratt et al., 2020; Turner et al., 1997).

Additionally, research has demonstrated negative associations between self-stigma and both self-esteem and self-confidence (Griffiths et al., 2012; Kent, 1999; Porter & Beuf, 1991). In a qualitative study, adolescents with various visible FD reported experiencing fear of being negatively evaluated, which hampered confidence in initiating relationships and even fears of becoming intimate (Griffiths et al., 2012). Furthermore, research has shown that people with FD have higher rates of depression or anxiety than people without FD (Gibson et al., 2018; Halioua et al., 2017; Hunt et al., 2005), and depression and anxiety are related to self-stigma. For instance, in a study on rosacea, people who reported feelings of stigmatization also reported more depressive symptoms (Halioua et al., 2017).

More generally, self-stigma impacts quality of life (Germain et al., 2021; Jankowiak et al., 2020; Masnari, et al., 2013; Strobel & Renner, 2016; Topolski et al., 2005; Visram et al., 2019). In a study conducted among people with psoriasis, Jankowiak et al. (2020) showed that the more sensitive individuals were to the opinions of others and the worse their attitudes about their psoriasis, the worse their quality of life was.

### 2.2.1. Summary

Overall, there is some research on self-stigma and its effects, but little research has directly measured the consequences of self-stigma and even less has explored the mediating role of stigma on quality of life outcomes (see, e.g., Van Der Kooij et al., 2021, for an example of an application to HIV stigma).

### 2.3. Stigma by association

Stigma can also affect people who do not have FD themselves but are, in some way, associated with someone with FD through stigma by association (Pryor & Reeder, 2011). Indeed, stigma can spread to people (i.e., companions) that are arbitrarily and closely related to individuals with FD, and this is especially the case in highly intolerant individuals (Neuberg et al., 1994; Pryor et al., 2012; Sigelman et al., 1991). Having a family member with a stigmatized condition or identity can lead to feelings of shame regarding the relationship, blame regarding the onset of the stigma, and fear of being contaminated by the stigma (Corrigan & Miller, 2004; Roozen et al., 2020). This can have severe implications as people are apt to be reluctant to build relationships with people with FD for fear of stigma. This clearly jeopardizes social opportunities (Crocker & Garcia, 2006). In terms of research, stigma by association can be studied either from the perspective of the companions (e.g., family, relatives, and/or partner) or from the perspective of the person who stigmatizes someone associated with a person with FD (i.e., the perceiver).

In the FD literature, most studies exploring stigma by association focus on families with a specific attention to the perspective of parent(s) or sibling(s) of a child with FD (Lehna, 2013; Strauss et al., 2007). That research shows that parents may feel 'different' because of their child's FD (Nelson et al., 2012) and that they experience discrimination in their social environment (for a review, see Nelson, et al., 2012). Similar to their child, they experience staring (Rossi et al., 2005), questions and comments (Kerr et al., 2020), and rejection (Nelson, et al., 2012). At the same time, family members may also feel 'unseen' when relatives act with neutrality as this can be (mis)interpreted as a lack of interest (Johansson & Ringsberg, 2004).

Research on the perspectives of other associates such as friends or intimate partners has also been conducted. Although controversial, studies on dating people living with disabilities have shown that one reason why individuals prefer dating people without disability is because they fear the reactions of their friends (Fichten et al., 1991; for an alternative explanation in terms of relationship satisfaction and inequity, see Collisson et al., 2020). Research has also shown that stigma by association is detrimental for companions (Dako-Gyeke, 2018). For example, in a qualitative study by Nelson et al., (2012) on parent's emotional and social experiences of caring for a child through cleft treatment, mothers reported worrying and feeling blamed for their child's condition, leading to feelings of guilt (Nelson et al., 2012). They also reported concerns about their child not being accepted or even bullied (Nelson et al., 2012). In another study, parents of children with vascular birthmarks reported having to deal with questions and comments that sought to ascertain the extent to which they may be responsible for their child's condition, which can be hurtful and upsetting (Kerr et al., 2020). Clearly, parents of children with FD have to navigate both stigmatizing reactions directed at themselves and stigmatizing reactions directed at their child with FD. Generally, these stigmatizing reactions emphasize abnormality and the undesirability of FD, or question the extent to which that child can meet beauty ideals (Kerr et al., 2020).

To our knowledge, there is no research conducted on stigma by association from the perceivers' perspective. However, given evidence that attitudes towards people with visible stigmas contaminate their companions (Pryor et al., 2012), and research showing that stereotypes towards people living with disabilities 'spread' to their partners (Goldstein & Johnson, 1997; Nieweglowski & Sheehan, 2017), it is likely that this phenomenon also occurs in interactions with associates of people with FD such as families, partners, and friends.

### 2.3.1. Summary



There is clear evidence that the stigma of FD can ‘spread’ to companions, and that companions grapple with both witnessing stigma towards their loved one and being stigmatized themselves because of their association with someone, often a child, with FD.

#### 2.4. Structural stigma

Structural stigma encompasses the ways in which society perpetuates and legitimizes the stigmatization of FD, notably by promoting ideal (face) shape in general, and, more specifically, by neglecting FD. The predominant source of structural stigma for FD is media. Media representations are important because they contribute to the beliefs and stereotypes about people with FD held by consumers of media (Garrisi & Janciute, & Johanssen, 2018; Gunter, 2012).

It is well documented that media influences body image through, for example, the mere exposure to socially imposed standards of appearance, or by inviting individuals to evaluate self-images posted on social media (for a review, see Jarman et al., 2022). Media content overwhelmingly praises ideal bodies and faces (e.g., thinspiration and fitspiration social media content; Griffiths et al., 2018) and scrutinizes less ideal ones (Frith, 2012). This idealization is particularly detrimental for people with FD for several reasons. First, it can lead to substantial body dissatisfaction, particularly among vulnerable populations (Ferguson, 2013; Puhl, 2022; Rodgers et al., 2020). Second, by promoting ideal body shapes, media contributes to the denigration of visible differences, thus shaping how people think about FD and framing visible difference as inherently negative and necessarily troubling (Rumsey & Harcourt, 2012).

On the whole, FD in the media is either not present or not well represented (Garrisi et al., 2018). There is a gross underrepresentation of visible differences, which contributes to a lack of public awareness, especially for rare conditions (see Riklin et al., 2019). When represented, the content tends to present a sensational or tragic depiction of FD (Garrisi et al., 2018). Indeed, most representations of FD in the media come either from reports on crimes or incidents that have led to FD through ‘before and after’ stories (Garrisi et al., 2018) or from entertainment (e.g., evil cinematic characters). Media

attention to some rare diseases occurs occasionally but very little attention is paid to more frequent forms of FD (e.g., acne vulgaris; Gunter, 2012). Furthermore, visible difference is almost completely absent in advertising which can lead people with FD to feel ignored and underrepresented (Changing Faces, 2021).

With regard to entertainment, almost all representations of FD in entertainment media frame the person with FD as evil (Partridge, 2012; Reese, 1995). Croley et al., (2017) compared the dermatologic characteristics of heroes and villains in the top ten American films and found that, in six of ten movies, villains had one or more skin disease, but none of the heroes had FD. This highlights how FD is used to illustrate moral depravity.

Clearly, media has significant impact in perpetuating structural stigma but structural stigma is also reflected in policy and legislation. Discrimination against, and human rights violations towards, people with FD are still neglected (Swift & Bogart, 2021). In many contexts, the rights of people with FD are not sufficiently protected (Saunders, 2020). This lack of protection concerns financial, medical, educational and other societal domains (Swift & Bogart, 2021). This is often because FD is seen as an individual issue, and as an individual problem that needs to be fixed. In this context, the propagation of surgery as the only viable avenue for living with FD is another reflection of structural stigma.

Indeed, surgery is put forth as the ideal, and an almost mandatory obligation, for people with FD. There are several possible reasons for this. First, unrealistic beauty standards have led to the medicalization of beautification and popularization of cosmetic surgery (Bonell et al., 2021; Wu, Mulkens, & Alleva, 2022), which offers the promise of an immediate and permanent solution to psychological distress. Second, reconstructive surgery has benefited from considerable technological progress offering an ever-expanding array of solutions. One example is the hope offered by the development of facial transplantation (Rifkin et al., 2018), alongside the fact that medical and surgical solutions often also provide a functional gain, thus lowering the stress elicited by disability and impairment (Bemmels et al., 2013; Roberts & Shute, 2011).

However, focusing ‘only’ on these solutions can lead individuals with FD to think that they must ‘fix’ the FD, and that the problem, and solution, lies with them. Beyond the significance of this therapeutic focus, people may also be dissatisfied with surgery, especially if the surgery has spillover effects (e.g., school absences), the social difficulties remain unchanged, or their post-operative look does not appear as “normal” as they had hoped (Bemmels et al., 2013; Myhre et al., 2021). Thus, the social pressure for people with FD to undergo surgery is problematic, especially for individuals for whom surgery is either not possible, not sufficient, or not wanted.

#### 2.4.1. Summary

Society plays an important role in the perpetuation of FD stigma, by promoting what people with FD are not, by not adequately representing people with FD in media and advertising, by negatively representing FD in media, by inadequately addressing human rights violations, and by perpetuating surgery as only viable avenue for dealing with FD.

### 3. Coping with the social stigma of facial difference

Evidently, in the context of facial difference, there is public stigma, self-stigma, stigma by association, and structural stigma, and each of these has detrimental social and psychological impacts. This necessitates coping on the part of people with FD and their associates like parents and siblings. People with FD may also benefit and improve coping with help of others (Griffiths et al., 2012; Habib et al., 2021). For instance, family members of people with FD can facilitate social participation (Bonanno & Esmaeli, 2012).

Link and colleagues (Link et al., 1989; see also Link & Phelan, 2013) identified three main coping orientations to face public stigma: secrecy, withdrawal, and education. Although FD is undoubtedly visible, many people with FD engage in measures to conceal their FD (e.g., cosmetic cream, prosthesis, surgery), often to ease outings in public places (Keys et al., 2021; Thompson et al., 2020) and in social

interactions (Bemmels et al., 2013; Myhre et al., 2021). Their stigma is thus partially concealed, because it may not be readily apparent to others. However, the mere presence of a ‘mask’ provokes reactions on the part of the perceivers (Yaron et al., 2018). As such, disclosure is frequently challenging for people with FD (Sharratt et al., 2020).

In addition to concealment, people with FD may also adopt avoidant behaviors and social withdrawal, in order to prevent stigma. However, this reduces opportunities to socialize and access social support (Griffiths et al., 2012; Halioua et al., 2017; Lanigan & Cotterill, 1989; Magin et al., 2008; Thompson et al., 2020).

For some people with FD, coping takes the form of educating people about their condition in order to ease social interactions (Bogart et al., 2012). To do this, resilience in dealing with negative reactions and comments is necessary (Thompson & Kent, 2001). Some individuals develop a more positive perspective by focusing on positive aspects of their FD, giving less importance to appearance, or accepting their condition as part of themselves (Bogart, 2015; Cash et al., 2005; Clarke et al., 2014; Griffiths et al., 2012; Habib et al., 2021; Visram et al., 2019). These strategies can be particularly useful for reducing self-stigma. One channel through which education takes place is through blogs. Blogs (e.g., <https://katiemeehan.co.uk>; see Garrisi & Johanssen, 2018) offer opportunities to broadcast one’s experience of living with FD, which both tackles negative representations of FD conveyed in the mainstream media, and replaces self-stigma with personal empowerment (Corrigan, 2019).

Indeed, there is research highlighting positive aspects of living with FD (Eiserman, 2001). Some of this work shows how FD makes its bearer unique, special, and recognized, which may be perceived as particularly positive in societies that value individuality (Kerr et al., 2020; Strauss, 2001). Other studies have shown that, despite stigma, a traumatic event – which may have led to an acquired FD - can bring about psychological growth and personal development, and actually increase well-being (Threader & McCormack, 2016). Accordingly, there is research showing that optimism is associated with reduced fear of negative appearance evaluation (Costa et al., 2021). A perspective whereby FD is studied and viewed as a strength rather than a weakness is clearly desirable, both because it fosters

optimism in those affected and their relatives, and because it better enables us to develop innovative treatments, psychological interventions, and ways to promote well-being and healthy relationships (Broder, 2001; Kerr et al., 2020; Meyerson, 2001; Mouradian, 2001; Roberts & Shute, 2011).

Coping with FD stigma can also be leveraged through body positivity movements. Body positivity movements often use social media as a mass communication tool to share information and to elevate attention to rights activism (Puhl, 2022). Given that people with FD use social media to find information and to access emotional and social support from others with FD (Stock et al., 2018), the body positivity movement is an integral part to coping with FD stigma and developing a positive social identity. Moreover, social media allows us to target structural stigma of FD by, for example, revaluing FD as an asset, reclaiming disability labels as positive subcultural signifiers, and establishing new norms, values, or dimensions of comparison (Nario-Redmond, 2020).

With respect to stigma by association, families may respond in ways similar to people with FD, such as withdrawal or concealment (Bonanno, 2012; Kerr et al., 2020; Nelson et al., 2012). Stigma is distressing and thus often a motivation for parents to seek medical or surgical advice (Williams et al., 2003). Research has shown that this differs for mothers and fathers. Fathers tend to be less concerned about being judged by others, while mothers tend to experience more social support (Nidey et al., 2016). It is also possible that parents acknowledge positive impacts of their child's condition (for a review, see Nelson et al., 2012). For example, the experience of being a parent of a child with FD can offer an opportunity to recognize one's own personal strengths and the strengths of one's child, which can lead to stronger relationships, or can increase a sense of community (Nelson et al., 2012).

### 3.1. Summary

People with FD cope with stigma using various approach and avoidance strategies including concealment, withdrawal, and education. Body positivity movements have also been leveraged to cope and empower people with FD. Associates of people with FD cope in similar ways as well.

## 4. Addressing the stigma of facial difference: How to intervene

There is a significant evidence base for stigma reduction interventions (Stutterheim et al., 2022; Stutterheim & Ratcliffe, 2021) that have been tested and demonstrated efficacy across various stigmatized identities and conditions including sexual orientation (Bartoş et al., 2014), mental illness in general (Corrigan et al., 2012), eating disorders more specifically (Doley et al., 2017), weight (Rubino et al., 2020), tuberculosis (Sommerland et al., 2017), HIV (Mak et al., 2017), and health-related stigma more generally (Stangl et al., 2019; for a review see Paluck et al., 2021). As such, the broader stigma literature can offer insight on how to best tackle stigma related to FD (for a review, see Stutterheim & Ratcliffe, 2021).

With regard to FD, much research focusing on the social difficulties encountered by people living with FD provide practical implications (for a review, see Rumsey & Harcourt, 2004). Yet, we believe that bridging together social stigma and the FD literatures can foster the development of innovative intervention strategies and/or the improvement of already existing ones. To this end, we detail, below, interventions addressing the different types of stigma in parallel to interventions targeting FD difficulties.

### 4.1. Interventions for public stigma

Interventions are needed in order to tackle the public stigma of FD and its accompanying cognitive (e.g., stereotypes; Jamrozik et al., 2019), affective (e.g., disgust; Shanmugarajah et al., 2012), and behavioral reactions (e.g., avoidance; Ryan et al., 2012). These interventions should aim to reduce automatic negative reactions, while promoting more deliberate and positive ones (Pryor et al., 2004), regardless of the context.

Strategies that have been developed to reduce and prevent the public stigma of FD have mostly focused on information provision and contact with affected groups (see Topp et al., 2019). The provision of information can be important (e.g., through education campaigns, notably for rare diseases) (Bogart & Tickle-Degnen, 2015), but, generally, strategies promoting contact are more

effective than information-based ones (Corrigan et al., 2018; Topp et al., 2019). Contact interventions lead to the disconfirmation of stereotypes and are particularly effective when the contact is between people of equal status, when the interactions are one-on-one, and when the interaction involves an activity that is rewarding or includes a shared goal (Corrigan & Shapiro, 2010). However, indirect contact through videos can also improve social judgments of individuals with FD (Edwards et al., 2011; Stone & Fisher, 2020).

Education-based strategies have also been developed in order to ease social interactions between people with FD and people without FD that they see on a regular basis (e.g., caregivers, professors, colleagues; Hlongwa & Rispel, 2018; Rumsey & Harcourt, 2004). For instance, reintegration programs for children with burns are improved when they also help teachers to manage the situation, including their own reactions (Pan et al., 2018).

Specifically with respect to cognitive reactions to people with FD, strategies enabling people to challenge their beliefs or biases towards FD are imperative. Bogart and Tickle-Degnen (2015) showed the beneficial impact of a training to 'look beyond' FD. In their study, participants who were informed, trained, and provided with feedback on cues for interacting with people with facial paralysis displayed better performances in impression formation (Bogart & Tickle-Degnen, 2015). Other strategies include cognitive training, which aims to alter particular cognitive associations (e.g., FD with villains; see Paluck et al., 2021). Cognitive training can be applied to emotional reactions, and lower associations between FD and negative attributes (Bilici et al., 2022). Furthermore, strategies fostering empathy, such as perspective-taking (Todd & Galinsky, 2014), have been found to be effective (Batson et al., 2002). Perspective taking also has beneficial behavioral outcomes, fostering approach-oriented action tendencies and smoother interactions.

#### 4.2. Interventions for self-stigma

Strategies that can effectively address self-stigma include cognitive behavioral therapy (CBT) and skills building (Topp et al., 2019). Indeed, the provision of psychological services can be beneficial

for the reduction of both anticipated and internalized stigma. By training individuals to identify and modify negative beliefs and interpretations, CBT addresses not only internalized negative beliefs about FD; it also helps people with FD deal with consequences of self-stigma and develop coping skills (e.g., behavioral therapy) (Heijnders & Van Der Meij, 2006; Mittal et al., 2012).

Strategies that seek to develop social skills or provide tools for social interactions can also serve to manage enacted stigma (e.g., training conversation skills, identifying others' reactions, using compensatory strategies; Clarke, 1999; Jenkinson et al., 2015; Robinson et al., 1996). Furthermore, self-help interventions that have been designed to lower appearance-related distress may also lower self-stigma (Muftin & Thompson, 2013). This includes interventions that target stress reduction with mindfulness, or resilience with self-compassion. Additionally, peer support can enable people with FD to find new ways to manage self-stigma by sharing experiences (Bogart et al., 2017; Bogart & Hemmesch, 2016).

Research on other stigmas can also provide insights for the development of new strategies and the refinement of existing strategies for addressing FD self-stigma (for a critical review on self-stigma reduction strategies, see Mittal et al., 2012). For example, there is substantial evidence showing that Acceptance and Commitment Therapy (ACT) can successfully reduce internalized stigma, both when employed in isolation (Luoma et al., 2008) and when combined with CBT (Pearl et al., 2020). More generally, ACT is a psychological flexibility-based intervention, which can lessen self-stigma by increasing psychological acceptance and lowering self-conscious emotions (e.g., shame; Masuda et al., 2017).

#### 4.3. Interventions for stigma by association

Strategies aimed at counselling families and helping them to deal with their family member's FD have proven to be valuable in reducing stigma by association (e.g., Positive Parenting Program, parental training; Costa, et al., 2021). For instance, the Early Family Intervention Program was designed to support parents of a child with a disability and has demonstrated evidence for better adaptation,



including reduced emotional distress (Pelchat et al., 1999). More generally, providing peer support to close relatives is advantageous, especially for mothers (Nidey et al., 2016).

To be effective, strategies targeting stigma by association should aim to help relatives build resilience and coping skills. As such, strategies for addressing public stigma or self-stigma can also be employed to reduce stigma by association. More broadly, there is a substantial need to support relatives of people with a stigmatized identity or condition, as demonstrated by a study conducted with family members of people with mental illness. This study showed that emotional support (e.g., discussing feelings), instrumental support (e.g., information, advice) and organizing support systems (e.g., networks) can be life-changing (van der Sanden et al., 2014).

#### 4.4. Interventions for structural stigma

Several approaches can be used to prevent structural stigma and to protect people with FD against the impacts of structural stigma. Given the important work conducted by the charity Changing Faces, we draw heavily on their work in our recommendations for reducing structural stigma. First, we recommend changes to policy and laws, and the recognition of the rights of people with FD. Changing Faces has lobbied for ‘disfigurement’ to be covered by the Disability Discrimination Act 1995 and the Equality Act 2010 (Changing Faces, 2017) and we support this. More generally, advocacy is needed in order to support the interests of people with FD.

Second, in order to improve knowledge and generate more positive attitudes towards FD in society, increased awareness and positive exposure to facial conditions is needed. This has, to some extent, been done. For example, in an effort to tackle the ‘disfigured is bad’ stereotype, there have been public awareness campaigns that focus on positive exposure (e.g., see Changing faces’ campaign ‘I am not your villain’ in the UK, or Corasso’s campaign ‘Quoi ma gueule ?’ in France). Increased awareness also requires educating and training the media on best practices for addressing FD (Garrisi et al., 2018). For instance, Face Equality International (2021) provides resources on how to present,

interview, and talk about FD. Furthermore, we suggest explicitly calling on the media to produce and commit in non-stigmatizing portrayals of FD (see Rubino et al., 2020).

Third, because structural stigma causes social exclusion, we need inclusive efforts that remove the barriers that reduce people with FD's opportunities to participate in social life (e.g., discrimination at work, school). These efforts should also seek to increase the visibility of people with FD. For instance, the Changing Faces' (2021) campaign 'pledge to be seen' aims at representing more people with a visible difference in communication.

#### 4.5. Summary

We have a broad toolbox for addressing public stigma, self-stigma, stigma by association, and structural stigma. These strategies can be derived from not only previous experience and efforts to reduce FD stigma, but also efforts to reduce stigmatization related to other identities and conditions.

## 5. Conclusion

In this paper, we set out to employ the social stigma framework put forth by Pryor and Reeder (2011) to unpack the stigma of facial difference (FD). By describing relevant literature on public stigma including the cognitive, affective, and behavioral reactions to people with FD; self-stigma including anticipated and internalized stigma; stigma by association experienced predominantly by parents of children with FD, and structural stigma embedded in media and in legislation, we have shown the utility of Pryor and Reeder's (2011) framework for understanding FD stigma. We then followed up by discussing how people with FD cope with the various forms of stigma. Lastly, we outlined a number of evidence-based strategies for addressing FD stigma. In doing so, we hope to have shed light on future avenues for intervention and the improvement of well-being for people with FD.

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