

# PERCEPTIONS OF STIGMA EXPERIENCES: MULTISITE STUDY OF MOTHERS AND CHILDREN WITH FACIAL DIFFERENCES

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# Issues

- The impact of appearance on adolescent social life
- Stigmatization
- Social, and media norms

- How much does appearance function as a determinant of life experiences?
- Does appearance affect quality of life and social experience?

# Stigma, Erving Goffman, 1963

- Bodily signs of being different carry a moral evaluation, usually a negative one.
- Theory of stigmatization.
- First impressions are transformed into normative expectations, and then into firmly held roles and responsibilities.

# The Face

- Immediately observable
- Principal target of attention in interpersonal interaction
- “everyday after I brush my teeth, I’ll stare in the mirror and see something I never like about me.” – 14 y.o. male

# Purpose of this study

- Profile the stigma experiences of adolescents with congenital and acquired facial differences.
- Compare adolescent perceptions of stigma experiences with parental perceptions.

# Methods

- Self-administered questionnaires
- Closed ended questions; 8 stigma items
- Baseline, cross-sectional data
- 4 sites : Seattle, Chicago, Galveston, & Chapel Hill
- N=185
- 60% male
- English Speaking
- 11 – 18 years old
- All had facial differences – 80% congenital
- Mothers (n=152); asked 8 matching questions also asked of their child

## Feel Unwelcome

**Q: During the past 4 weeks, how often have people your age made you feel unwelcome because of how you look?**

(Child wording)

**Q: During the past 4 weeks, how often have people your daughter/son's age made her/him feel unwelcome because of how she/he looks? (Parent wording)**

### YOUTH

Never	61%
Almost Never	16%
Sometimes	12%
Fairly Often	4%
Very often	7%

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**Sometimes, Fairly Often, Very Often** 23%

# Youth Responses

“Sometimes, Fairly Often and Very Often”

- 23% Made to feel unwelcome by peers in past month.
- 35% Noticed people staring at their face in the past week.
- 28% Talked with others about how their face looks in the past month.
- 29% Heard others say something about their face in the past month.
- 32% Told peers about their facial difference in the past month.
- 12% Felt left out of doing things with peers because of how their face looks in the past month.
- 11% Got into fights because of how their face looks in the past month.
- 20% Were teased about how their face looks in the past month.

# Youth/Mother Responses

“Sometimes, Fairly Often and Very Often”

23%	24%	Made to feel unwelcome by peers in past month.
35%	47%	Noticed people staring at their face in the past week.
28%	43%	Talked with others about how their face looks in the past month.
29%	31%	Heard others say something about their face in the past month.
32%	32%	Told peers about their facial difference in the past month.
12%	12%	Felt left out of doing things with peers because of how their face looks in the past month.
11%	8%	Got into fights because of how their face looks in the past month.
20%	18%	Were teased about how their face looks in the past month.

# Male/Female Responses

“Sometimes, Fairly Often and Very Often”

17%	31%	Made to feel unwelcome by peers in past month.
26%	49%	Noticed people staring at their face in the past week.
19%	42%	Talked with others about how their face looks in the past month.
19%	43%	Heard others say something about their face in the past month.
29%	35%	Told peers about their facial difference in the past month.
6%	20%	Felt left out of doing things with peers because of how their face looks in the past month.
7%	18%	Got into fights because of how their face looks in the past month.
15%	28%	Were teased about how their face looks in the past month.

# Male / Female Trend

- Males report less stigma experiences than females.

# Congenital/Acquired Responses

“Sometimes, Fairly Often and Very Often”

20%	33%	Made to feel unwelcome by peers in past month.
29%	60%	Noticed people staring at their face in the past week.
25%	42%	Talked with others about how their face looks in the past month.
27%	37%	Heard others say something about their face in the past month.
30%	37%	Told peers about their facial difference in the past month.
10%	20%	Felt left out of doing things with peers because of how their face looks in the past month.
11%	11%	Got into fights because of how their face looks in the past month.
20%	22%	Were teased about how their face looks in the past month.

# Congenital / Acquired

- A trend noted that acquired conditions appeared to initiate more stigma experiences than did congenital conditions.

# Summary of Stigma Experiences

- Reported by up to 35% of youth with facial differences.
- Youth and mother generally shared perceptions
- Females tended to elicit more
- Acquired conditions tended to elicit more

# *Q: When Does Appearance Become Important?*

- By age 7, children make judgments about physical attractiveness in peers which bear close resemblance to adult perspectives.
- Being attractive becomes a social “good”
- When stigma becomes enacted by peers.

**In America we'd like to believe that  
we make our own opportunity ... that  
environment, not genetics or  
appearance makes us who we are.**

- When appearance changes so do other personal attributes and aspects of social life ... including stigma.
- Medical impetus to normalization is forceful.

# For Clinicians

- Recognize stigma
- Be aware of its impact
- Give an opportunity to talk about stigma
- Intervene with counseling or peer support
- Understand when no further treatment is desired
- Talk to employers, schools, insurers about stigma and discrimination

# Could public media be used to re-build norms and expectations?

- Advertising
- Film
- Theatre

**We have an opportunity to move beyond stigma, and to promote positive healthy and diverse contexts, within which acceptance and resilience are both enacted and felt.**