What Women with Facial Differences Told Us About Other's Reactions

Social norms change when you have an unusual appearance. Sometimes, the boundaries of socially acceptable behaviour are not clear. "People feel that you owe them an explanation."

In speaking with women with facial differences about their experiences of marginalization and stigma, these were the recurring themes.

Questions

By the time they reached adulthood, the women we talked to had developed a somewhat sophisticated understanding of different age groups' responses to their physical difference. For example, there was a recognition of the difference between a question asked in a respectful versus an intrusive manner. One woman told us about a co-worker: "This guy had an arrogance about him and . . . this one time he goes 'What happened to your eye?' just out of the blue . . . I was used to the kids doing that but when an adult did it I was totally offended."

Women often understood children's questions as stemming from innocence and curiosity. "Whenever a child asks me a question then I just take the attitude it's good because then they're noticing me as a person . . ."

Staring

The women in the focus groups distinguished between staring that was seen to be innocent and curious, and that which was felt to come from a sense of repulsion or fascination with the unusual. For example, compare one woman's experience: "My little niece is almost five, and when she sees my scars, she says, 'Oh auntie!' . . . But she is just concerned, she wants to make sure it doesn't hurt", with what another woman told us: "And then when I met her for the first time, she rudely called her sister to come over and have a look at my face."

Stereotyping

Women also spoke about the subtle forms of discrimination they experienced. This happened in social situations where other people made comments — "Oh, she's not gonna want to go there anyway because she looks different and it's gonna make her feel uncomfortable" — and in the workplace — ". . . the manager would introduce everyone around me to the people from the States, and he didn't introduce me."

Verbal Harassment

Verbal harassment was a constant experience that occurred throughout women's lives. Women spoke about being harassed in school, in the workplace, as well as public places. "I was riding on the subway ... and one of the young lads said to me 'Gee, are you ever ugly'." Another woman shared this: "[I've] been called Cyclops, one-eyed monster . . ."

Physical Violence

We know from our work with girls and women with facial differences that physical violence is often preceded by staring, teasing and bullying. Some of the women participating in this project had experienced physical violence related to their appearance. In the situations they described, it was boys who were known to the woman (or girl) with a facial difference who behaved violently. These were not strangers, nor did the women know them on a personal basis, but they were boys from the community. "I had the experience when I was a little girl, from young boys. They got hold of me . . . and they tied me up to a tree. And they were going to light a fire onto me, which terrified me something terrible. It was so bad that at one point I screamed."

Women understood the staring, verbal harassment and negative stereotyping as arising from other people's discomfort of physical difference. Their words describe it best: "People's reaction is they see you, they see that you're somehow different, and their mind is on how frail the human body really is. And it's a scary experience . . ." and "People are not willing to . . . you know, they're afraid. I think that's the word to use. They are afraid."



Roseline

Being born with a facial difference (bilateral cleft lip and palate) as well as other physical differences presented me with many challenges.

I had speech difficulties and was treated as a "slow learner". By October of my

first school year, I was moved back to kindergarten. I was confused by this because I already knew my numbers and how to write my long name. This was a blow to my confidence and self-esteem. Later a compassionate teacher (who was also my speech therapist) helped by reminding me that I was only physically handicapped, not mentally handicapped.

Still, growing up was emotionally painful. I wanted to die because inside I felt so alone. When adults discussed my medical treatment or my future in my presence, I was not encouraged to take part in the dialogue. I learned to "tune out" and stuff down my feelings. I turned to alcohol to numb out the pain of loneliness, frustration and anger.

One day a priest from my church introduced me to a group of people who helped me turn my life around. It was then that I was made aware that I must be willing to change my attitude. I learned to accept my physical differences and change how I viewed myself. I let go of the victim role and took charge of my life.

Today when someone happens to be staring, I smile genuinely – a big improvement for me because at one time I would stick out my tongue! Today I'm proud of who I am. I know that my physical and facial differences are my unique markings. I now know other people with facial differences and we share our experience, our strength and our hope which helps our spirits to grow in a positive light.

The Effects of Other's Reactions on Women: Short and Long Term Impacts

The negative experience of facial difference is part of a wider issue – a value system that focuses on a narrow definition of beauty and judges people by the way in which they do or do not meet that narrow definition. This divides people into categories of "us and them".

In general, we found that negative experiences related to appearance caused women to feel "different" in an undesirable way, stigmatized. Here is how one woman described it: "Unless something comes up I don't really think about this stuff too much. I think about it if someone stares at me on the subway or if you meet somebody and you don't know whether you need to explain."

Many of the women in the focus groups understood stigma as rooted in a fear of difference. How women understood other people's discomfort influenced the ways in which the women dealt with negative reactions to their appearance. Negative messages about appearance interfered with a woman's sense of belonging, or feeling good about herself. However, through these experiences women also developed effective coping skills, and greater insights and strengths. The ways in which women responded fell under two general themes as outlined on the following pages.

THE GENEROUS SUPPORT OF THE
GOVERNMENT OF ONTARIO THROUGH THE
MINISTRY OF CITIZENSHIP, CULTURE AND RECREATION
IS GRATEFULLY ACKNOWLEDGED.

THIS PROJECT ALSO RECEIVED A GRANT FROM THE

CANADIAN WOMEN'S FOUNDATION

IN PARTNERSHIP WITH

THE SEARLE WOMEN'S HEALTHCARE VIOLENCE PREVENTION FUND,

THE CANADIAN PACIFIC FOUNDATION, AND THE

CANADIAN WOMEN'S FOUNDATION VIOLENCE PREVENTION FUND.

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FACE Values

Women, Body Image and Facial Differences

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WITH SPECIAL THANKS TO
FRAN ODETTE, HELEN ARMSTRONG
AND LUCY COSTA NYMAN
FOR THEIR
KNOWLEDGE AND SUPPORT.

ABOUTFACE AND THE REGIONAL WOMEN'S HEALTH CENTRE

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