



A B O U T F A C E[®]

The Importance of Language and Communications for Practitioners

AboutFace has consulted with facial difference community members of all ages to create this resource, focused on language usage and communications, for practitioners working with facial difference community members. This may include healthcare and dental practitioners, social workers and social service workers, educators, and more.

Facial Difference and Equity

More than two million people in Canada are living with a facial difference. A person with a facial difference refers to anyone whose appearance, from the neck or above, has been affected by a congenital (from birth), acquired (after birth), or episodic (comes and goes) condition or syndrome.

The facial difference community encounters significant challenges to participating in society and is an equity-seeking group. Barriers and marginalization of the facial difference community have been created through stigma, people's attitudes, negative stereotypes often perpetuated by media and entertainment, environmental factors, and historical mistreatment of people who are perceived as different by society.

Identifying and addressing these barriers is critically important to addressing equal access to opportunities and resources.

For practitioners, understanding the importance of language and communications, particularly how negative and problematic language reinforces barriers and discrimination, is a key component to creating an inclusive practice focused on building equity and opportunity for people with a facial difference.

Recognizing Facial Difference Community Members

Individuals with a facial difference may refer to themselves as follows:

- A person with a facial difference
- A person living with a facial difference
- Facially different
- A person with a specific condition or syndrome – for example, a person with Sturge Weber Syndrome, a person with cleft lip, or a person with vitiligo

AboutFace encourages you as the professional and/or practitioner to use the terminology preferred by the individual that you are treating or working with (the patient or client).

AboutFace recommends that you ask the patient or client how they refer to their facial difference, at your first meeting or appointment. Your mindful approach in asking this question – *How would you like me to refer to your facial difference or status as a person with a facial difference?* – will create an inclusive and respectful space for your patient or client. Be sure to use the patient’s or client’s preferred terms moving forward.

Facial Difference and Intersectionality

The facial difference community is made up of individuals from every province and territory and includes people from many equity-seeking groups. The intersectionality of the facial difference community includes Black people, Indigenous peoples, people from racialized communities, members of the 2SLGBTQIA+ community, refugees, and other diverse and underrepresented populations. Recognizing the unique and intersectional needs of the community is critical to building safe, inclusive spaces where individuals feel respected and comfortable.



Facial Difference and Disability

Members of the facial difference community in Canada may identify as follows:

- Disabled under the traditional definition of disability
- Facially different, but not disabled
- Disabled and facially different, noting the intersectionality of two separate identities
- Disabled as defined by the social model of disability.¹

Patients may have preferred terminology in relation to disability and how they identify, including:

- A person with a disability
- A person with a disability *and* a facial difference
- A disabled person.

Some patients or clients may choose to use words that are meaningful to them. For example, some patients in Canada, when working with healthcare professionals, prefer to use the word *disfigured* because it is a terminology widely understood in the medical community. Or, people from other communities might use other language or terminology based on their personal experiences within the medical and treatment models. Additionally, people whose first language is not English may have alternative words that they use to describe their facial difference.

As noted above, AboutFace encourages practitioners to adopt the preferred terminology of the patient or client they are treating or working with, to help create safe and inclusive spaces.

¹ The social model of disability notes that people are disadvantaged not by the person’s impairment or difference, but rather by society’s response and barriers. This can include people’s attitudes to differences, like assuming a person with a facial difference cannot do certain things, as well as society’s failure to accommodate differences.

Words and Phrasing to Avoid

The facial difference community has identified words and phrasing that are hurtful and contribute to the deterioration of trust between practitioners and community members. Words like disfigurement, anomaly, defect or birth defect, malformation, and deformity have negative connotations. Community members noted these words are cruel and hurtful and that the use of negative terminology affects their interactions with practitioners and their mental health and self-esteem.

AboutFace recognizes that, historically, many of these words have been used in the medical model of care, social work fields, or education. We encourage practitioners to adopt language that is more empowering and factual.

Here are some examples of how to use appropriate words and phrases:

- Instead of referring to a cleft lip and palate as a facial disfigurement, refer to it as a facial difference. *“My patient’s facial difference is a cleft lip and palate.”*
- Instead of referring to a birthmark as a defect or anomaly, refer to it as a birthmark. *“My client has a birthmark on their cheek.”*
- Do not refer to a patient by their facial difference, such as *“the Moebius Syndrome patient.”* Instead use, *“the patient with Moebius Syndrome.”*
- Do not use the word just to describe someone’s conditions. For example: *“It’s just a birthmark”* or *“It’s just a scar.”* The use of the word *“just”* undermines the concerns of your patient or client and invalidates their experiences.

By avoiding these words or phrases above, you will build a practice that is mindful of your patients or clients.

Other Communications Best Practices

Building an inclusive practice for your patients or clients with a facial difference is important, here are some other best practices.

COMMUNICATE DIRECTLY WITH PATIENTS OR CLIENTS

Speak directly to your patient or client. Facial difference community members of every age encourage practitioners to speak directly to them, rather than to someone who may be accompanying them to an appointment (for example, a parent, caregiver, or interpreter). Even young children with a facial difference have a desire for practitioners to speak directly to them about their condition, surgery, treatment, and/or accommodations. By speaking directly to your patient or client, you will build a respectful relationship and empower them. This practice will help to normalize and role model a safe way for family members and caregivers to discuss facial difference among themselves and with others.





ADOPT TRAUMA-INFORMED CARE

Trauma-informed care is based on the assumption that all patients or clients may have experienced trauma in their life. The goal of trauma-informed care is to create a safe environment that will avoid further traumatization or re-traumatization.

Patients or clients with facial differences, or other complex medical conditions, are more likely to have experienced trauma from previous treatments and/or from discrimination. In addition, patients or clients may have experienced unrelated personal trauma or experienced other forms of systemic oppression, such as racism, or other forms of structural and historical violence.

Trauma-informed care does not require knowing the patient's or client's trauma or "fixing" their trauma. It is instead focused on creating a supportive and safe environment. By recognizing each patient's or client's needs for physical and emotional safety, care professionals provide choice and control in the treatment process.

ACTIVELY LISTEN

Listen to your client or patient when they are speaking and indicate your understanding of what they have said by asking relevant questions or summarizing what they have said. This includes maintaining appropriate eye contact.

COMMUNICATE CLEARLY

When providing information, use concise, clear language, based on a person's age and general understanding. When appropriate, provide medical and/or technical information as clearly as possible, without too many buzzwords or jargon. If your patient or client requests an explanation of specific words, please provide an explanation, as this helps empower patients and adds to their knowledge about their health condition or syndrome. Be open to questions and actively listen during conversations.

CREATE POSITIVE ASSOCIATIONS

Professionals will have a significant impact when they create positive experiences for patients or clients. These experiences can shape the tone of future conversations for patients or clients, both with other medical professionals, in similar physical settings or spaces, and with others in their lives. Here are some ways you can do this:

- Give your full attention to patients or clients – let them know you are their sole focus during their appointment.
- It's okay to give genuine appearance-based compliments or kind observations. Some examples include *"I like your new haircut"* or *"are those new earrings?"*
- Ask about all aspects of care, including physical, mental, and emotional health. A simple *"how are you?"* at the start of an appointment shows welcomeness. Other more personable questions may help build rapport, for example:
 - o *"What's different or better than the last time I saw you?"*
 - o *"Tell me about your favourite hobby."*
 - o *"What is your favourite part of school, and what are some things that make school hard for kids?"*

CONSIDER AND RECOGNIZE UNCONSCIOUS BIAS

Find time to check-in with yourself and fully register your own reactions when you meet someone with a facial difference. What are your assumptions or beliefs about their appearance or difference? What are your hopes and fears for this patient or client? You may feel shocked, uncomfortable, angry, concerned, or touched with pity by a person whose appearance seems unusual. Be mindful of recognizing your own reaction when seeing something new. For example, many people will have an initial reaction of staring, and then feeling guilt, which cause them to look away or avoid looking back again. Recognizing your own attitudes and biases about appearance and facial difference will help you better support your patient or client.

BE MINDFUL OF SYSTEMS OF OPPRESSION AND DISCRIMINATION

The AboutFace website is full of information and resources concerning facial difference and working with the facial difference community. These resources are useful for understanding the systemic barriers that community members encounter. By educating yourself you will help build understanding, and this will help you build a practice with a holistic approach to care and support.



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Who We Are

AboutFace is a national charity and our mission is to cultivate equity and opportunity for individuals with a facial difference through supportive programming, advocacy, and education.

If you would like more information or support, please contact us or visit aboutface.ca.

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