

Coping with the stigma of craniofacial disorders

<http://www.aboutkidshealth.ca/En/News/NewsAndFeatures/Pages/coping-craniofacial-disorders-stigma.aspx>

In many ways, our faces are our identities. We face the world, put a good face on things, face facts; people we don't like may be two-faced or boldfaced liars. For better or worse, our faces are what people first see about us and what we see in the mirror. Children with a facial difference such as cleft lip with or without cleft palate, microtia (a condition in which the external ear is not fully formed, which often occurs together with atresia, or absence of the ear canal), asymmetry, or malformed features have a unique set of challenges.

Coping with the stigma

The word "stigma" comes from a Greek word meaning a mark or brand. It's an appropriate term, therefore, for what children who are visibly different from their peers experience. In some cultures, a facial difference such as a cleft lip literally marks a child as cursed or evil. While children in North America are unlikely to be cast out of their families or banished from their towns, they do face stares and comments. They will probably meet people who are uncomfortable around them or who assume that they are stupid. They may also encounter teasing and bullying. Our society's premium on physical appearance may also make them more vulnerable to low self-esteem and poor body image, especially for pre-teen and teenage girls.

"I think people don't realize how important the stigma is," says Heather Beveridge, a social worker with the Craniofacial Program at The Hospital for Sick Children (SickKids). "You're always exposed; your teeth are affected so your smile is affected. Cleft lip and palate are known, but a lot of other syndromes are rare and not well understood."

Parents of a child with a facial difference must deal with the reactions of others, which may range from surprise to hurtful comments, starting when their child is a baby. Other children start to notice that a child is different around Grade 1. Children and adults with a facial difference have to work harder at social skills, meeting people, and connecting with others, but they can manage very well. "They have amazing empathy for others," says Kim Tiemens, also a social worker with the Craniofacial Program.

Surgical correction

Another challenge for children with a facial difference is surgery; many will go through several surgeries at different times in their lives. It's important to talk with children beforehand about their expectations of surgery, and to be clear about what surgery can and cannot do. "Some kids really want perfection, for their face to be completely 'fixed' and for the 'problem' to go away," Tiemens says.

This expectation isn't always realistic. Surgical intervention involves a number of procedures, and some children need to wait until they are teenagers before the last surgery can be done. Even then, the results may be different than they imagined.

The change in a child's appearance after surgery can be drastic. Even if the new look is "better" than before, children may need help getting used to it. "Your face is your identity," Tiemens points out. "Children see their new face and wonder, 'does this change who I am as a person?'"

How can parents help?

Tiemens and Beveridge offer pointers for parents of a child with a facial difference:

- Have open conversations. When parents struggle with their child's facial difference, so does the child. "If parents shy away from the issue and don't answer questions about it, the child gets the idea that it's bad and shameful," Beveridge says.
- Make sure your child understands that usually staring isn't meant to be hurtful; people may simply be caught by surprise.
- Help your child explain to others why she looks different. A calm explanation may be all that is needed to short-circuit teasing, which often stems from ignorance.
- Recognize and praise your child's abilities and strengths, and help her to develop them. Encourage her to develop a skill or hobby or to take part in a sport. Doing something she feels good about will help to bolster her self-esteem and confidence.
- Help your child build a good support network of friends.
- Realize that while our society puts great value on physical appearance, perfection is hard for anyone to achieve.

Parents may also need to advocate for their child at school to make sure she is challenged enough and that she gets help for any learning disability, hearing difficulty, or speech problems.

It's a good idea to seek advice and support from other families. "Lots of parents have amazing ideas to share on coping and helping their child, because they live it," Tiemens says.

About craniofacial abnormalities

Facial differences are often present at birth. AboutFace, a support group for people with facial differences and their families, estimates that more than 100,000 babies in North America are born with a facial birth defect each year. Facial differences may be caused by anything that affects the way the bones, muscles, and tissues in a child's face and skull develop. Causes include genetic conditions such as Apert syndrome, Crouzon syndrome, and Treacher Collins syndrome, as well as abnormal development in the womb.

The best known type of facial birth defect is cleft lip, with or without cleft palate. However, facial differences can take many other forms, including:

- abnormal shape, size, or position of features
- underdevelopment of some bones of the head and face, resulting in an asymmetrical face
- premature closing of skull sutures

Later in life, people may develop facial differences due to injuries or disease. AboutFace puts this number at over 500,000 people in North America each year.

Children with facial differences may also have vision problems, hearing problems, or speech problems, either as a result of their facial difference or because of related abnormalities. Other parts of their body may also be affected, including the skeleton, the heart, the central nervous system, or the genito-urinary tract.

Onlookers frequently assume that a child with a facial difference is also mentally disabled, especially if she needs a hearing aid or other help. While this is true in some cases, children with a facial difference often have normal intelligence. "Many parents have to work really hard to convince the school that while their child may need some extra supports, overall he or she is just like the other children," says Tiemens.

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Further reading:

AboutFace [homepage on the Internet]. <http://www.aboutfaceinternational.org>