



# Nationellt nätverk för kraniofaciala missbildningar

## **Strategies for individuals with facial disfigurement, their families, and professionals in health care based on focus-group sessions**

### **Strategies for parents**

- Inform the child when a change in education level is to take place, for example, before starting day care, kindergarten, school, a new school class, an after-school activity, or a new sport.
- Inform other parents in the day care group and school class about your child's condition.
- Try to find leisure time activities and special interests or hobbies in which your child can participate and do well.
- Talk to your child about the reactions of others to his or her appearance; talk with him or her about ways of responding when someone stares or asks questions. Show that it is natural to talk about these things.

### **Strategies for teenagers**

- Educate yourself about your diagnosis.
- See to it that you yourself are part of discussions about your treatment. Ask questions about the result of a certain operation or treatment and how it will affect your situation if you refuse treatment.
- Think twice about what you yourself think is important to improve or change.
- Think of why you do or do not want treatment.
- Try to find persons to talk to, such as family members, friends, or teachers.

## **Strategies for health care and habilitation professionals**

- Inform the family in detail about the diagnosis that is set for their child and what it means in terms of treatments, operations, training and so on.
- Try to mediate contact with another family in which a member has the same diagnosis.
- Inform the family of helpful resources, for example, support groups, journals, books, and films.
- Go through the information again with the family, and check that they understand.
- Strongly encourage the child to participate in discussions on operations and treatment starting at about five years of age.
- Inform the child again at 8–10 years of age and during the teens.
- Individualize all treatment.
- Encourage the child and family to ask about the risks and consequences of having an operation or treatment as well as of refusing to have that operation or treatment.
- Encourage the child and family to get a second opinion before making difficult decisions.