Strategies for living with facial disfigurement

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Aim: Individuals with rare craniofacial disorders seem to be particularly at risk of negative social experiences and are often confronted with staring, questions and prejudice. Impaired speech, vision, hearing, and sometimes also cognitive abilities can make communication difficult. Ten years of involvement with a multi-professional network, The Swedish network for craniofacial disfigurement, whose purpose is to improve the way individuals with craniofacial disorders are received in health care, day care, and school situations, has disclosed dissatisfaction among affected individuals and families. The aim of this project was to sum up the experiences from conferences on living with facial disfigurement into recommendations aimed to improve the reception of affected individuals in health care and daily life.

Material and Methods: To capture their views, focus groups were formed with young affected individuals and with parents to children with facial anomalies. The main themes at the meetings were: – What makes you feel as if you are an active participant in your/your child’s treatment and in decisions being made about treatment? – What makes you/ or your child feel as if the persons you meet respect you? Suggestions for strategies expressed by affected individuals and families in the focus groups were compiled and divided into categories.

Results: The views expressed in the focus groups were grouped into three categories: strategies for parents, for teenagers, and for professionals. The aims of the strategies are to empower persons with facial disfigurement and their families in treatment planning and performance, and to strengthen affected persons by teaching them to be proactive. The three sets of strategies are well in line with international recommendations in health care and with the UN Convention on the Rights of the Child.

Conclusion: The general conclusion was that it is not lack of specific knowledge but rather lack of implementation of existing recommendations that still makes living with facial disfigurement difficult for many individuals and families.