

## **Pediatric Facial Plastic and Reconstructive Surgery**

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### **Chapter 25: Facial Plastic and Reconstructive Surgery in Children: Its Impact on the Psychological Development of the Child and Recommendations for Surgery**

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#### **The Emotional Impact of Craniofacial Disorders**

##### **What is an "Attractive" Child?**

What do we mean by "attractiveness"? Suppose we take for an example the case of 4-year-old Molly, with silky brown hair, large brown eyes, and regular features. Molly turns from the mirror to her mother with a sad expression on her face. "I'm ugly", she says. Her shocked mother asks her how she could say such a thing. "I wish I had blond hair and blue eyes like Cinderella", Molly answers. Incidental to this conversation was the birthday party of Molly's 2-year-old brother.

Four-year-old Karen, who has Crouzon's syndrome, comes for a clinical appointment with pastel barrettes carefully placed in her dark hair. Her flowered cotton shirt and shorts outfit includes a junior version of stylish shoulder pads, and her tiny feet are fitted with pink sandals. In spite of the anomalous configurations of Karen's head and face, she seems to feel good about herself and feel proud of her appearance.

These examples illustrate the kinds of observations all of us, but especially those of us who work with "disfigured" children, have struggled to understand. How can we make sense of these contradictions? What conceptual tools do we have? Social psychological theory can help us understand the reactions of people to deviance or stigma; such reactions must contribute to the self-image of a disfigured child. Developmental psychology can help us understand the factors making up self-image in the developing child. Finally, psychoanalytic theory can help us understand the unconscious processes that give symbolic meaning to disfigurement and impairment.

#### **Social Psychology**

What kind of responses can children with facial deformities expect from those around them? In his classic work on "stigma", Goffman defines stigma as "undesired differentness" of which physical deformities are one type. He refers to the ancient Greeks' use of the term to signify marks on the body, or brands, identifying the bearers as people to be avoided. Indeed, studies have shown that people attribute negative characteristics such as lack of intelligence, or even dishonesty, to those with facial disfigurements. In a corresponding manner, they are likely to attribute positive characteristics to people with "attractive" faces. Studies have shown that children as young as 3.5 prefer "attractive" peers as friends and associate unattractive children with "antisocial" behavior. These findings are consistent with the relationship between stigma and morality described by social theorists. This notion that

good is associated with beauty and bad with ugliness is demonstrated in myths and literature throughout the ages, for example in many fairy tales and in literary villains such as Shakespeare's Richard III.

### **Developmental Psychology**

Developmental psychology, on the other hand, gives us knowledge about the ways a child learns about himself and others and about the preeminence of the face in building human relationships. Infants prefer looking at the human face to looking at other visual patterns. Perhaps one of the reasons for the importance of the human face to the infant has to do with the way emotion is communicated through facial expression. In cross-cultural studies Ekman and Izard have demonstrated there is a universal ability to identify basic emotions such as happiness, sadness, anger, and fear in schematic drawings of a human face.

The fact that the infant registers the configurations of the face in contrast to the facial features alone is revealed by the findings of Field et al, who have shown that 2- to 3-day-old infants can discriminate and imitate smiles, frowns, and surprise expressions in the face of a person interacting with them. The earliest loving attachment between infant and mother is accomplished through facial expressions and vocalizations. This bond has gained prominence recently in the field of "attachment theory", a specialized area of developmental psychology. Attachment theorists relate security in this earliest relationship to successful emotional development and self-esteem throughout life.

Other contributions to our understanding from the field of developmental psychology include ideas about how infants organize perceptions about their environment, and observations about when children begin to recognize themselves through physical appearance. "Amodal perception" is a concept described by Stern, which refers to the process by which an infant associates similar patterns across different types of sensory modalities, such as auditory and visual stimuli delivered at the same frequency, in order to make generalizations about his environment. Could this characteristic of learning relate to the preference infants demonstrate for symmetry in the vertical plane, as in the human face? That children learn to recognize their own visual image between 15 and 24 months of age has been found by a study in which a rouge spot was put on a child's nose and then the child shown his reflection in a mirror. Three-quarters of the infants exhibited mark-specific behavior between 21 and 24 months of age; none of the 9- to 12-month-old group appeared to notice this deviance from their characteristic appearance.

### **Psychoanalytic Theory**

Returning to our example of the two 4-year-old girls, we are better prepared to comment on their "attractiveness". We know that Molly and Karen have a clear "facial identity" by now, and have a sense of how their faces compare with the norm. They have used their faces and their mothers' faces to establish an "attachment" relationship and to communicate emotions within this relationship and others. We could guess that cultural stereotypes might in part explain Karen's positive self-regard with respect to her stylish and feminine attire, and Molly's negative evaluation of her fair hair and eyes. However, we are still left with mysteries. Is Molly's lack of resemblance to the Walt Disney image of Cinderella enhanced by her perceived difference from the fairy tale heroine? How do we explain Karen's

apparently positive self-esteem?

Using psychoanalytic theory we can make some hypotheses about Karen's unconscious thoughts. Perhaps her jealousy and anger at her little brother, who has just had a birthday party and who has arrived at an age when he can become a more active and bothersome competitor, has made her feel like a bad girl. Now, a bad girl could not possibly be a Cinderella, and therefore, she could not be beautiful. However, these unconscious ideas can be elaborated even further to help us understand children with disfigurements and functional impairments. Children also associated "defectiveness", which can refer to both disfigurement and functional impairment, with loss.

Regardless of whether or not the defect involves a concrete loss, children with body defects see themselves as missing something or as being vulnerable to missing something. This "have-not" image includes feelings of being "bad" or unlovable, which are organized around the body defect. In other words, the child unconsciously feels there is something bad and unlovable about them *that has to do with* the defect. This does not mean that children with a body defect cannot have good self-esteem or see themselves as lovable. It only means that whenever they do feel bad about themselves, they are likely to relate that bad feeling to the body defect consciously or unconsciously. For example, a 4-year-old girl with a large facial birthmark told her parents that she could never be the Madonna in the Christmas play because of her birthmark. Like Molly in the first example, this child had a little brother and felt guilty about her hostile feelings toward him. It was not only the Madonna's beauty, but also her goodness that this little girl was (unconsciously) referring to. Another child with a disfigurement due to a traumatic injury, felt guilty about angry, competitive feelings toward her mother, whom she saw as having "everything" (husband, career, baby). She played a game in which she tried to find something missing inside a doll, and drew a picture of herself as, in her wonderful descriptive term, "an ugly stepmaid".

### **The Emotional Impact of Craniofacial Anomalies on the Developing Child**

Now that we have outlined several conceptual models with which to study the emotional impact of craniofacial anomalies, we may proceed to a consideration of the influence of these defects on the child's developmental achievements and sense of mastery. To do this it is helpful to organize the discussion according to different ages of the child and to think of the child not alone, but in relation to his environment: his family, peers, community, and society. Taking a look at the child in this context is important because the effect of the facial anomaly is the result of a reciprocal process. As we shall see, in addition to the stage-specific tasks facing these children and their families at each developmental stage, they are also challenged with the disappointment that comes with having an "imperfection". Although we all have imperfections, facial anomalies are particularly obvious and do not go away. These children and their families go through repeated experiences of mourning.

#### **Infancy**

The birth of an infant with a disfigured face requires the parents to confront the loss of their fantasized "ideal child". This fantasy is part of normal family development and carries healing and hope to all families expecting a baby. Instead of the usual slow process of giving up the idealization of the perfect child, which occurs for families of healthy children bit by

bit during the course of childhood, the parents of the defective newborn must precipitously and painfully give up their fantasy of perfection. All family members acquire some of the negative valuation of the stigma just by virtue of the association with the disfigured child.

From the point of view of the infant's development, there is now some evidence to support what has long been hypothesized, that the presence of a craniofacial anomaly in a newborn can interfere with the normal attachment process. Functional difficulties with eating, vision, hearing, or vocalizing can also affect attachment by diminishing the satisfaction of the feeding experience on the part of both baby and mother, by interfering with the powerful mutual activity of gazing, and by affecting the reciprocal vocalizing that forms another important aspect of bonding. It is also difficult for extended family and community, even society at large, to welcome a defective baby. Everyone shares in the hopefulness of the ideal child fantasy, and confrontation with an obviously imperfect infant destroys this fantasy immediately, leaving anxiety in the place of pleasure. Not surprisingly, there is evidence that the birth of a stigmatized child restricts the social life of a family.

### **Preschool Period**

The period from 1 to 5 years of age is an active time of practicing separation from parents and exploring the world in a limited setting. The child often goes to nursery school, an extension of family life and a part of the small community of early childhood that includes new caring adults and a group of peers. There is evidence that nurturing parents and a protective community can foster good self-esteem development in the stigmatized child during this stage of life. However, outside the comforting familiarity of these groups, the child with a facial disfigurement may not be well received by his peers. Even preschool children express awareness of disabilities, and by 3.5 years of age have demonstrated a negative reaction to facial disfigurement.

Pertschuk and Whitaker found parents of young children with craniofacial deformity to exhibit none of the "rejecting and overprotective" behavior suggested in the anecdotal literature. This is consistent with many observations of good adjustment in young children with craniofacial disfigurement and in their parents. However, Pertschuk and Whitaker's study did show much poorer functioning in their older age groups. In addition to the suggested explanation of different societal challenges faced by their older and younger groups, the study may also suffer due to failure to take into account subtle interactional factors in the family that can lay the groundwork for anxious or inhibited behavior in later childhood.

Anxious and controlling behavior on the part of parents, as well as unwelcoming responses from other children, can cause problems in separation, which is the primary developmental task of this age. For example, it may be harder for parents to encourage their disfigured child to go to school against his will than it would be for a less vulnerable child. Functional impairments, especially as they involve speech, vision, or hearing, will clearly put the handicapped child at a disadvantage in school. They will also threaten other children, who will identify with the appearance of incompetence. Finally, they will complicate the efforts of both parents and teachers to make realistic expectations for the child. If the child is clinging and unwilling to participate, or if the child demands special attention, it may be hard to tell when to accommodate the child's expressed needs or when to set limits. Aggressive behavior may also pose a problem from this point of view: How much can the child control

by himself, and how much is the behavior a natural response to provocation?

In contrast with aggressive behavior, children with craniofacial deformities appear to withdraw, inhibit their impulses, and become dependent in response to feeling vulnerable. This pattern of behavior, although adaptive in some ways, may set the course for future problems by restricting the child's repertoire of coping responses and putting a cap on ambition and risk taking, as well as negatively influencing self-esteem. In my experience, the school community and society tend to be quite tolerant of children of this age with a facial deformity. Once the initial threat of the disappointment at birth has passed, and the competitive pressures of the school years have not yet begun, people generally extend a benevolent and protective attitude toward these children, perhaps particularly because they are often compliant.

### **School Age**

School years present an even greater challenge to the child with a facial deformity and his parents, as demands for autonomy and performance in social and academic areas increase. Society tends to be less tolerant of school-aged children with a deformity. Societal values stress successful performance and conformity, rather than diversity. Peers continue to register a preference for nondisfigured children as friends, and functional impairments present a greater disadvantage to the child in terms of school performance, and to his teachers and parents in terms of making realistic expectations of him. As one might expect, studies show that children with craniofacial deformities have poorer academic performance, greater separation problems, and lower self-esteem than other children.

### **Adolescence**

Adolescence poses particular problems for the facially deformed child. As earlier, the separation task is complicated by the presence of a deformity, which makes the child vulnerable in several important ways. There is a high likelihood of being rejected by peers; adolescents and young adults are progressively more negative about disabled peers. It is hard for the deformed child to fit the group ideal. Conformity to a group ideal facilitates the separation from parents and, through identification with this ideal, allows for the development of one's individual identity. It is harder for the disabled adolescent to succeed in his schoolwork because academic performance is more competitive, in preparation for the demands of adult life in this society. All these factors put pressure on the parents, who worry about their vulnerable child, who is soon to leave the scope of their protection. Setting realistic expectations for behavior and performance at this stage is another major problem, as the stakes get higher and the demands for the child to function autonomously increase.

Sexual development presents a new challenge to the adolescent with a facial disfigurement. Worries about being attractive to the opposite sex and anxiety about changing body image often focus on the deformity. A woman with a facial birthmark reported that as an adolescent she lost interest in clothes because "All people looked at was this (the birthmark) - what did it matter what I wore?" The feelings of rejection and failure she experienced led her to "drown her troubles" in alcohol and delinquent behavior. Anxious about her developing woman's body, another girl with a birthmark joined a fundamentalist religious group that taught "It's what inside that counts".

New demands on parents for limit setting are complicated not only by adolescents' tendency toward action, but by their greater need for independence and responsibility. The need to mourn the "perfect child" presents itself again with a vengeance at this stage. Instead of the young man or woman who is prepared to go out and conquer the world, the parents of the disfigured adolescent see their beloved child as older, but clearly imperfect, still facing harrowing possibilities of rejection and failure. Parents with greater capacity to tolerance the powerful mix of feelings this awareness stirs in them, hate as well as love, are better able to do the requisite mourning and let their child grow up.

### **The Questin of Surgery**

#### **The Surgeon as Consultant**

The first step in making decisions about surgery is to clarify the surgeon's role as consultant to the family in making decisions. Staying carefully within this role can avoid grave problems as well as make it possible for the surgeon to work effectively. The role of the consultant is to use special expertise to answer questions. This is different from the role of the surgeon in the operating room, or during most of the time he is taking care of patients. It involves finding out what questions the patient and family want answered, how these questions can be modified to create questions that can realistically be answered, and, finally, answering the latter questions. The answers usually include a recommendation about what action to take. Staying within the role of consultant helps the surgeon avoid (a) making unrealistic promises, (b) attempting to rescue a patient, and (c) giving the patient unwanted advice. It is hard to make a serious mistake if one pays careful attention to one's role as consultant.

#### **Whether or Not to Do Surgery**

There are two main issues related to surgery: whether or not to do it, and when to do it. In order to answer either question, the family unit must be assessed. Four questions must be answered. (a) What are the family's goals with respect to surgery? (b) How are decisions made in the family? (c) How does the family deal with frustration and disappointment? (d) What are the family's resources?

#### ***What are the Family's Goals?***

This question represents an effort to determine whether surgery can realistically satisfy the patient and his family. The surgeon is in a good position to predict what the surgical procedure could offer. Is this consistent with what the family wants? In the best situation, the child and family have a long-standing relationship with the surgeon and have discussed the possibility of surgery for some time. They have talked often about the kind of surgical result that might be realistically expected. In this case, the family's goals for surgery are usually consistent with the average, expectable result.

In other cases, where the situation is not so clear, when the surgeon does not know the patient and the family so well, there may be a hidden agenda. Sometimes the "hidden agenda" is conscious, such as a lawsuit in the case of a traumatic injury or a previous surgery with "unsatisfactory" result.

Other times the motive is unconscious. For example, an adolescent with a Natalie Wood-like nose requested a rhinoplasty to restore her nose to its larger, hooked, original shape, the way it was before a previous rhinoplasty. She explained that she could not recognize herself with her present nose, that she felt "lost" and hopeless. Psychiatric interview revealed an unconscious motive, without which her requests for surgery were incomprehensible. She had requested the original rhinoplasty in an effort to rid herself of, to use her words, her "mother's nose". When this was accomplished, she felt she had lost "her mother in her". Her unconscious feelings about her mother were actually very ambivalent and included a powerful longing and dependency toward her mother mixed in with her conscious anger and rejection. Thus when she "lost her mother", she became depressed and could not rest until she restored her mother within herself in the form of her original nose.

### ***How are Decisions Made in the Family?***

If the surgeon inquires about how the family makes other important decisions, he may discover that the family approaches the problem together, includes the child in the decision-making process in a manner appropriate to this age, and comes to a consensus that everyone can support. On the other hand, he may find that the parents make the decision independent of the wishes of the adolescent patient, or expect a 6- or 7-year-old child to decide for himself. He may uncover a marital conflict that centers around the decision, with mother on one side and father on the other. Identifying these problems early may avoid unnecessary complications later on. Generally speaking, the young school-age child is too immature to take on the responsibility of the decision of whether or not to do surgery for facial disfigurement. His opinions should be elicited, but not in the context of whether or not the procedure will actually be done. Around the age of 8 the child begins to be prepared to take a more active role in the decision making. Nevertheless, it is not until mid- to late adolescence that the child becomes the primary decision maker.

### ***How Does the Family Deal with Frustration and Disappointment?***

Problems can arise when families are unable to confront their disappointments and frustrations and struggle with the painful realities in order to make peace with them. For example, the parents of a child with a traumatic injury came to the psychiatric consultant with the request for psychotherapy for the child, who was said to be depressed as a result of his injury. After some weeks of evaluation sessions, the parents began to complain about the inconvenience of taking the boy to his sessions. Since the child was indeed depressed, the parents' complaints did not seem consistent with their original request for treatment for the boy's unhappiness.

Through the course of the evaluation the psychiatrist had learned that the father had been out of work for some time, and the couple was having marital difficulties related to the father's work problem. It seemed that the family was ready to break apart. The parents said that the father's previous employer was to blame for his having to leave his job. However, it was clear from other remarks that the mother joined the father's blaming the employer in order to avoid blaming him. Her own father had abandoned the family when she was a child, and she was afraid to focus her rage at her profoundly disappointing father onto her husband, because that might mean that she would have to leave him. Further questioning revealed that the boy's school was being sued for the injury, and that the family's agenda for the

psychiatrist was not psychotherapy, but litigation support. Indeed, it seemed that the family's method of dealing with disappointment and frustration was to blame someone else, and this blaming behavior, actualized in the litigation, got in the way of their attempts to mourn their real disappointments and get on with their lives. The boy's depression reflected his parents' interference with his efforts to come to terms with his injury.

### ***What are the Family's Resources?***

By "resources" I mean not only the financial means to pay for the procedure. I am also referring to the network of support the family can call on in times of need. Extended family, friends, church, community groups, and agencies are all of potential help during the stressful time of the hospitalization, and in the healing time afterward. All of us have seen hospital rooms decorated with cards, banners, plants and flowers, etc, that testify to the caring community supporting the room's occupant. These are the same communities that take care of the family's other children so that the mother can stay in the hospital with the patient, who do errands for her and help feed the family, and offer emotional support to the family. The family in the example above had alienated its neighbors with its attack on the school and found itself as isolated in the community as the family members were isolated from one another. The vulnerabilities of such a family can be contrasted with a family that has been able to develop strong supportive relationships within the community. These supports can make a real difference to the success of surgery. Exploring the possibilities of such supports with a family in relation to planning a procedure can sometimes help the family identify them and get them into place.

### **The Timing of Surgery**

A key issue in the decision about surgery is the timing of the procedure. When I first began consulting to pediatric surgeons, in the early 1970s, the prevailing belief of child psychiatrists and psychologists was that surgery should be delayed as long as possible because of the traumatic consequences of hospitalization and painful procedures to the young child. This belief developed in part from the pioneering work by child psychoanalysts with children who were chronically institutionalized, children who had been separated from their parents during World War II, and children who were institutionalized temporarily for reasons such as the birth of another child. The belief also derived from early psychoanalytic theory, which stressed the long-lasting effects of childhood traumatic experiences on the personality, and emphasized parental separations and abandonment, as well as physical pain imposed on the helpless child, as prototypical traumas of this type. It is generally agreed that hospitalization and surgical procedures are more stressful for the young child, eg, younger than 7, than for older children. This is especially true for children who do not yet have language to organize their experience and to communicate with their environment. Does this mean that surgery should be delayed until adolescence in most cases?

In fact, waiting until adolescence is not usually recommended. The traumatic potential of hospitalization has changed significantly. Even as recently as the early 1970s, it was rare for a parent to be able to stay with the child overnight in the hospital. Now, "rooming in" is frequent. The observation that the child was more compliant in the parents' absence was frequently attributed to a problematic parent-child relationship such as poor parental limit setting, rather than to a worrisome "submissive" defensive behavior on the part of the child.



Now, the child's "fighting back" is recognized as a sign of health, which can be controlled without being crushed. Psychiatric consultation in most hospitals in the 1970s had not yet developed to the point of offering the surgeons the specialized information necessary to understand the effect of the cognitive limitations and defensive distortions on the young child's perception of what was happening to him. Now, many surgeons have expert psychiatric consultation to help them appreciate their young patients' perceptions and capacities for cooperation and taking responsibility.

At the same time, surgical technique and the scientific knowledge supporting it have improved tremendously. It is now possible to improve the appearance and reduce the functional impairment of congenital anomalies much earlier in the child's life, sometimes in early infancy. My experiences as consultant to the plastic and reconstructive surgery team helped me appreciate the benefits of reconstructive surgery early in a child's life, benefits that include an improved aesthetic appearance for a larger portion of the child's development. My consultations also led me to appreciate the complex nature of the human response to facial disfigurement.

There has long been talk of "sensitive" periods in a child's development, when disruptive and potentially traumatic experiences such as surgery should be avoided. Yet an argument can be made for many such "sensitive" periods and there is little "hard" evidence for any of them. Certainly, the support available to the child is a necessary consideration in any evaluation of sensitive periods. Can the factors of abandonment by parents, loss of comforting routine of home, confusion, and frightening fantasies about what is happening to him or her be minimized or mitigated? Parent "rooming in", flexibility of ward routine to suit the needs of the individual child, and hospital social and psychological supports for the child and family can all modify the "sensitivity" of the child to a surgical procedure. There are, however, a few general comments that can be made about "sensitive" times: (a) The second half of the 2nd year of life is a time when the child consolidates his sense of himself, a time when many different developmental paths converge in a burst of integration. It would be better not to disrupt this important developmental moment. (b) At ages 3 to 5, children are particularly vulnerable to anxieties about body injury. They are struggling to manage their aggressive impulses, and are apt to interpret surgical interventions as retaliations for their "bad" out-of-control aggression. This would be a good time to avoid. (c) Preadolescence, which occurs at about 11 to 13 for girls and 12 to 14 for boys is an especially vulnerable time in terms of body image. Children of these ages are very anxious about whether or not their body is all right, and they often feel confused and out of control in relation to their bodies.

Even these statements about sensitive periods should be used only as general guidelines to alert the surgeon to developmental changes occurring at these stages. Many children will go through these changes at ages different from those I listed. This is especially true of children with body defects, who are often somewhat delayed in their emotional development. Psychiatric consultation related to this point may be useful.

### **The Argument for Early Surgery for the Sake of Psychosocial Development**

What about the idea that improving a facial disfigurement spares the child problems with his psychosocial development? Even very good surgical results do not completely erase the deformity, and social psychological theory provides evidence for the fact that slight facial

disfigurement is a powerful stimulus for rejection of the disfigured person. Some observers have noted that objectively minor disfigurements often have powerfully disadvantageous effects on social and psychological adjustment. If the detrimental effects of early hospitalization and surgery are not offset by the advantageous effects of improved aesthetic appearance offered by early surgery, should postponement be the rule?

In search of an answer, let's return to the example of "Karen". Karen came from a middle-class family with a warm, mutually respectful marital relationship and strong social supports. Older children in the family had done quite well in school and provided the parents with a sense of having a successful family. Now the parents's self-esteem focused on doing "the best we can" to help Karen "develop according to her potential" and to "help other people realize what a wonderful person she is". They experienced the surgeon as helping them do their job of being good parents to Karen. First considering and then planning the surgical procedures made them feel less helpless as parents of a child with a problem. They considered the results of her surgery a real improvement, but the objective results were only part of what helped them feel successful. Fortunately, they also struggled with the continuing awareness that they would never achieve a perfect result. There were ups and downs for them as for all parents in comparable situations. Where does this lead us?

Although the development of self-esteem in relation to body image has unfortunately not been studied in a careful, systematic way, some things are clear. Self-esteem in the disfigured child is not solely a function of the objective disfigurement, not even of the social reaction to it. The child's self-esteem is also a function of the family's capacity to deal with the demands created, and the disappointment represented by the deformity. Regardless of the sensitivity of society to subtle signs of disfigurement, the parents' estimation of the improvement, coupled with their sense of mastery over the helplessness they felt in relation to their defective child, may have a powerful impact on the *family* self-esteem and thus on the self-esteem the child derives from being a valued member of that family. "We did everything we could do", is a major satisfaction to add to even a minor aesthetic improvement. This knowledge on the part of parents marks a turning point that initiates the necessary mourning.

## **Rules of Thumb in Making Decisions About Surgery**

It is helpful, perhaps, to summarize with a few rules of thumb for the use of the surgeon in his role as consultant in recommending surgery:

1. Make an estimation of the successful outcome of surgical intervention for a particular facial disfigurement or functional impairment.
2. Identify the points in time during the physical development of the child or of the deformity when surgical intervention would be optimal from the point of view of the surgical technique.
3. Assess the capacity of the child and the family to make a responsible decision about surgery, to gather the requisite supports, and to deal with frustration and disappointment.
4. Balance the advantages of interventions early in the child's life on improvement of physical appearance and enhanced family self-esteem, against the problems presented by the particular vulnerabilities of the young child, which require special supports during the hospitalization and in the extended recovery period.
5. When possible avoid the "sensitive" periods of 18 to 24 months, 3 to 5 years, and 11 to 13 in girls and 12 to 14 in boys. Remember that these "sensitive" periods are approximations and may be different for different children. When in doubt, a psychiatric evaluation may help in this assessment.

## **Best Case, Worst Case Examples**

### ***Best Case #1***

Betsy was a 9-year-old girl with a large facial hemangioma that had faded to the point of being a slightly darker shade of her skin color. A good student with many friends, Betsy was a sensitive child who had problems with separation from her parents, but who generally did well and enjoyed her life. Her parents had some rocky times in their marriage, but they were strongly allied in support of their child's healthy development and worked well together to support her. They had many friends and a helpful extended family. Betsy and her family had a long-term relationship with the same surgeon, who had followed Betsy's problem with them since early infancy. Together, they had anticipated the points at which surgical intervention might be helpful, and had been through the decision-making process before. Twice in the past they had considered surgery and decided to put it off, first because there was not high-enough probability of a good surgical result, and second because the disfigurement did not seem to interfere enough with Betsy's life at the time. Now, in anticipation of adolescence, and with a good surgical result highly probable, the "team" of Betsy, her parents, and the surgeon, decided to schedule the surgery.

### ***Best Case #2***

Jody M's parents were both physicians and had long awaited their first child. When Jody was born with a severe cleft lip and palate, both parents were distraught. The surgeon's immediate response to the referral from the neonatologist was a source of great relief in the crisis. Although the reality of chronic disfigurement of some degree and the possibility of multiple interventions could not yet be encompassed, the first surgical repair made it possible for Dr M to bond to Jody, and renewed the hope that had been destroyed in the shock of the birth experience.

### ***Worst Case #1***

A 12-year-old girl came with her parents for consultation about a congenital abnormality of her nose and chin. She was obese and unkempt. Her parents said that she had always suffered from her poor appearance and that they had been told that surgery could "fix" it before she went to high school. Since she had already been scapegoated in elementary school, they were worried about her entrance into junior high, which had a reputation in their town for being tough. The parents had made application for her to go to a private school, and although the girl refused to go to private school, the parents said that if she got in, they would make her go, "for her own good".

### ***Worst Case #2***

A 4-year-old boy with a diagnosis of "hyperactive" came for consultation about a congenital abnormality of his ears. His mother, a single parent, said that his ears had bothered her since his birth. They reminded her of his father, who had been abusive to her, and they made him look stupid. He had been hospitalized earlier that year for an emergency appendectomy, and he had been a real problem in the hospital, requiring physical restraints to keep him from dislodging his IV. During this hospitalization, the mother had complained

about his ears to the pediatrician, who had made the referral to the surgeon.

### ***Discussion of Cases***

These cases are designed to illustrate the main points in the "rules of thumb". The "best cases" illustrate the child and family who are capable of making responsible decisions, who have adequate supports, who have demonstrated capacity to deal with frustration and disappointments, and in which the child is not at a "sensitive" age. The "worst case" illustrate the child and family who are probably not capable of making responsible decisions together, who have inadequate supports, who have demonstrated difficulty dealing with frustration and disappointments, and in which the child is at a "sensitive" age.

### **Conclusion**

Children and their families are helped when the children look as normal as possible as early as possible. It is better for all children to have all the right equipment as soon as they can. Early intervention should be balanced against the negative effects of hospitalization, but it is often possible to minimize these effects through supports in the environment both inside and outside the hospital. Children with facial disorders cannot be evaluated without considering the family context. Surgery should be postponed or avoided if other problems in the child or within the family are being displaced onto the child's disorder. Under good circumstances, evaluation for surgery and surgery itself presents an opportunity for psychological growth that goes beyond the physical result of the surgical procedure. It can become a team effort including the surgeon, the child, and the parents. In replacing helplessness with hope, it can initiate the process of mourning the loss of the ideal child. Making peace with this disappointment can accomplish a step forward in an important maturational process, that of finding value in oneself as one is, and in the related process of learning how to find realistic satisfaction in life.