

The Impact of an Anomalous Child on Those Concerned with His Welfare*



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All of us have had the experience of feeling opposite emotions about a single occurrence, individual, or anticipated event. This is a normal human response which in psychological terms is known as feeling ambivalent. It is something that occurs whenever we are faced with a situation that is new and unfamiliar.

At the Child Amputee Prosthetics Project every staff member has had the experience of talking with and observing the reactions not only of the amputee patient, but of those who come into contact with him in his everyday life—parents, relatives, friends, teachers, therapists, doctors, prosthetists, and last, but not least, ourselves. Self-examination is always the hardest to perform but it can result in rewarding knowledge of attitudes and feelings that influence how and why we react in a certain manner toward a given individual or situation and why they in turn react as they do toward us. It helps us to know why we can have a sincere desire to help correct a deformity which either nature or later traumatic events have imposed upon an individual and at the same time, feel repulsed or otherwise uncomfortable about the condition. From our contacts and observations we have learned a great deal about the impact an anomalous child has on those who are concerned with his welfare. By examining the major crisis periods that occur in the

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life of an amputee child, we have gained a better understanding of what his life will be like as an adult in our society. We know from experience that the way in which the crisis is handled will determine to a large extent the kind of adjustment the child will make to his disability.

One of the most profound shocks that a human being ever experiences is the trauma of being born. At no other time can the human body withstand such drastic environmental changes such as heat exchange, circulation change and extreme pressures. But nature prepares for these physical insults by providing us with the necessary mechanisms to insure survival, in most cases. Nature does not prepare us for the emotional shock of observing or being informed that the child was born with an observable anomaly that is of a chronic, irreparable nature. From the information given to us by parents concerning how they felt at the time this occurred, two themes are repeated enough to be considered significant: 1) they felt entirely alone with their problem, and 2) that nothing could be done for the child.

When these feelings are examined it becomes clear that they stem from several sources. The shock of having produced an anomalous child brings forth immediate feelings of guilt, shame, failure and, in some cases, repulsion. With all of this, there may be an added wish that the child will not live. Parents who can be given immediate help from someone who has professional knowledge about their child's problem stand a much better chance of finding healthy ways of dealing with these feelings than parents who are left to grope alone with their overwhelming disappointment.

The question often arises as to how much help parents feel they were given by the attending medical staff at the time when their child was born. The answers vary from no help at all to a sincere gratefulness that the physician or other para-medical staff gave them the kind of support and understanding they so desperately needed. Unfortunately, we find that in the majority of cases, the reactions of the medical personnel parallel the reactions of non-professional people who become touched by this unexpected turn of events. Why does this happen? In few instances does the reason seem to stem from a lack of concern for a fellow human being. To the contrary, the most frequent cause seems to come from our natural desire to avoid pain—either for ourselves or others. When we know that a situation is going to produce tears, self-recriminations and other expressions of emotional disturbance, the easiest way to avoid it is to make ourselves unavailable through any number of ways—"There are so many other patients to care for," "Someone else can do the job better than I," etc. Another equally effective way to avoid having to cope with parental feelings is to stifle them with platitudes such as, "Time will erase your sorrow" or "You should be glad that it's his arms and not his mind."

The most important contribution that can be made at this time is to keep the channels of communication open and free of harmful attempts to conceal feelings which the family thinks are unacceptable. When parents can be helped to understand why they feel as they do toward the child and know that it is out of their concern for him as a human being burdened with an extra load to carry through life that they may wish he would not live, they are enabled to come through the shock with as little permanent scarring as is possible. The longer they carry their feelings locked tightly within them, the more severe and irreparable the damage. An example of this is the mother who several years after the birth of a child with multiple anomalies is unable to allow him out of her sight (except when attending a special school) for fear that something may happen to him. It was only

recently that she was able to tell us that after he was born and she was informed of the deformities, she was placed in a room by herself. Over and over the thought "Couldn't they get rid of it" repeated itself in her mind. Years later we see her defending herself from the guilt which this thought produced by being pathologically concerned about the child's health. At this point, the prognosis for any appreciable change in this mother's behavior is extremely poor.

One of the ways the Child Amputee Prosthetics Project has attempted to reach parents at the time of crisis is through early referral to and subsequent contact by either the physician and/or the social worker on the Project staff. At times, the therapists have also been involved. By early referral we mean seeing the parents before the mother and baby leave the hospital. However, this type of referral constitutes a small portion of our patient load. In the majority of cases several months, even years have gone by before the patient is brought to us for evaluation and on-going treatment for the disability. In the meantime, whatever professional ameliorative help has been given has usually come from the private physician, perhaps a therapist connected with another rehabilitation setting, a social worker in another agency, the child's teacher, the prosthetist in private industry or any combination of these resources.

What happens when parents come to us seeking help for their child? What transpires between parent and the helping person that will influence whether or not the help that is offered will be effective? In considering these questions, we must keep in mind what any of us think about when faced with a new situation. When talking with parents, and the child if old enough, recalling our own feelings about something that is unfamiliar will eliminate much of the misunderstanding that takes place because people are not able to adequately communicate their concerns to one another through words.

Parents often look upon medical and allied professions with awe. They feel that it is not permissible for them to ask questions or if they were to ask, that their questions would make them look stupid. This is especially true when we use the short-cut of professional jargon which serves to confuse rather than clarify what is being said. By encouraging parents and/or the patient to ask questions, we are often able to learn much more about how we can best begin to help them than if we proceed without knowing what it is about the disability that bothers them most. Related to this is the question of "Will I be liked?" Many times an individual refrains from asking a question that could be interpreted in a negative way for fear that in so doing, they will not be liked or accepted. When it is made clear that the individual has a right and a responsibility to ask questions, much of the tension is relieved.

Sometimes a simple explanation can prevent a parent or child from acting on the basis of false ideas. We recently had contact with an eleven year old youngster who was petrified with fright when her parents brought her to the Project for evaluation. During the course of the interviews, it was discovered that when she was six years old the parents had taken her to a prosthetics shop from which she ran screaming and begged them not to take her back. The parents interpreted this as merely her desire not to wear a prosthesis and pursued it no further. It was not until just prior to our seeing the family that the youngster admitted that her fears had been based on the idea that the prosthesis would be sewn to her. Years later she is unable to accept a prosthesis despite having now been given correct information.

We know from experience that people have different ways of expressing their feelings. Some withdraw into silence or monosyllable answers which do not reveal what is troubling them. In this instance, we must listen for what the person is not saying through his refusal to speak. Others become quite aggressive in their attack upon either the professional competency of the person rendering a service or on the tangible substitute which is made to replace the missing limb. Every prosthetist has experienced the situation of having a parent or child who is never satisfied with a prosthesis. After checking it over from a functional standpoint the prosthesis is shown to be working correctly and still the complaints continue. It is difficult to remember in these situations that the individual's complaints are not really directed at the prosthetist. They exist because the parent or the patient has never accepted the need for a mechanical substitute for the missing limb. Therapists have almost universally had the experience of dealing with parents who for one reason or another can never seem to keep the therapy appointments. Social workers are familiar with the mother who can find time to serve on the Boards of several agencies serving handicapped groups but makes no attempt to secure rehabilitative services for her own child.

These are but a few examples that can be cited as evidence that what people say they want and what they are really looking for are often two different things. People need to have time to wrestle with their decisions when doubts remain and a lack of conviction about the recommended program or device continues to plague them. It has been our experience that unless they are permitted to think over what is involved in a prosthetics program for themselves and the child, ill-timed or unwise decisions may result. An invitation for the family to go home, think about what they have seen and heard, and come back at a later time, has proven a valuable method of helping them reach a decision that will be consistent with what they want for the child.

We have made a beginning in learning how we can devise a program that will best serve our patients' needs. We have much more to learn. It is our hope and goal that through continued research, service and education we will produce new techniques and devices, attain greater proficiency through treatment in helping our patients to meet their own needs, increase general knowledge about child amputees and their problems and thereby attain our combined goal of patient habilitation.