

# Self-Understanding For the Parents Of Handicapped Children

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**T**HE PARENTS of all children—handicapped or normal—are interested in helping children grow into mature, self-reliant persons who have the capacity to contribute to, as well as to take from, the community in which they live. The success with which this objective is attained is to a considerable extent a reflection of the understanding which parents have not only of their children, but also themselves. For if parents do not understand themselves, they may, by superimposing emotional complications, increase the difficulties of children already subjected to a handicapping condition. This may minimize the child's effectiveness in dealing with his problems. Therefore, by increasing self-understanding of parents as individuals we in turn increase self-understanding among children with the result that better adaptation to the handicapping condition and to the community may be facilitated.

As parents grow in self-understanding, there are developed new and deeper insights into helping children to achieve their greatest potentialities. A parent may develop new skills with which to help the child, and also learn to provide realistically for many of the specific

needs of the child. But perhaps most significantly a parent can begin to understand that he may be limiting the child too much and thereby thwarting growth, or he may make the child insecure by asking too much from him at another time. Parents may increase their understanding to the advantage of the child in various ways. These group themselves about the significance of physical care; the development of independence; and self-understanding by sharing.

## Significance of Physical Care

Parents of a handicapped child have basic concern about the full significance and extent of the child's handicap. This concern may be obvious; often it is subtle. Parents of a child with a deformity uneasily ask their physicians rather diffuse and evasive questions about the condition when they really want to have some reassurance about not having any responsibility for the causation of the handicap. Particularly in the early days of adjustment to the full impact of the handicap, self-understanding stems from the sharing of one's doubts and anxieties.

The importance of an adequate program of medical care and ancillary services in all communities in order that all parents may be assured realistically that they are receiving the best possible help with their problems cannot be emphasized strongly enough. Certainly the impetus given by organizations such as the National Society for Crippled Children and Adults toward the nationwide attainment of high standards for the care of handicapped children has been a source of comfort to many parents. The program of providing scholarships of various kinds has made it possible for many communities to provide increasingly better services to the handicapped. Out of the continuity of care provided by professionally qualified personnel and from the reduction of doubts and anxieties, there develops a more effective relationship with children.

Out of an adequate medical program in which

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*Dr. Richmond, chairman and professor, department of pediatrics, College of Medicine, State University of New York, Syracuse, N. Y., gave the lecture on which this paper is based before the National Society for Crippled Children and Adults, in Chicago, November 13, 1953. He is a member of the board of trustees, Child Welfare League of America, and is on the editorial board of Psychosomatic Medicine.*

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parents have invested energy—and often money—come feelings of security in relation to the management of the child and also the courage to face the future. These can come in no other way. To illustrate, when parents of a child with progressive muscular dystrophy come to a physician he may be often embarrassed by the gratitude extended to him as a physician who admittedly is powerless—as are all others—to interrupt the progress of the disease. Physicians can begin to understand that these expressions of gratitude have real meaning when they stop to realize that in these visits the parents have had an opportunity to share their anxieties with physicians who have the most information, that they have been able to ask questions which all parents want to ask, and perhaps most significantly—that they have received reassurance that everything possible has been done to help their child.

Parents have the further reassuring factor that medical science is constantly discovering and seeking new information through research. Although research isn't often translated into personal terms, the support of research by parents or groups of parents provides them with hope, without which it would be difficult to face the future. Resources and energy often are expended heavily in the direction of service to patients while research suffers. As a physician and investigator, I must call to your attention that research is a very personal investment of all. For when research dries up, hope for the future vanishes.

### **Development of Independence**

To help children grow to maturity they need to be permitted to exercise increasing responsibility as age increases. Perhaps one of the greatest problems for parents in the rearing of handicapped children is the achievement of a delicate balance of understanding needed to determine how much responsibility is appropriate for the age and condition of the child. Overprotection ceases to be protection and may retard progress. Unfortunately, no rule of thumb can be employed with success; each child has his unique problems and rate of development.

Growth does not occur unless it is provided with building blocks. We have defined certain

building blocks for physical growth which have become well known in the form of proteins, carbohydrates, fats, vitamins, and minerals. The psychological development of the child also has building blocks. These are evidenced in the form of a sense of trust in him, respect for his individual differences, and stimulation to develop his greatest potentialities. This latter point could be defined as "accentuating the positive."

A sense of trust in the child develops from the security he feels in those about him. The understanding which parents manifest; the capacity for patience which parents need to await progress, slow though it may be; the pleasure which they share as progress develops—all contribute to the development of the child's sense of trust in his parents first, and subsequently in the world about him. For if parents cannot be understanding, accepting, and patient, their anxieties are communicated to the child and have added to his burden.

Parents of handicapped children encounter problems similar to those parents of normal children face in dealing with individual differences. That no two so-called "normal" children are alike is now appreciated. An understanding of the unique problem of each child, his developmental rate, the fact that he may undergo a spurt at one time just as physical growth occurs in spurts, are all helpful. There is no normal level to which children and parents need aspire. "Mass-production psychology" which would tend to lower our sights to a "lowest common denominator" represents an unwholesome trend which we hope has been reversed. In order to understand the child's individual patterns, parents must learn to temper preconceived notions of what they expect children to do. This sometimes requires help from professional personnel outside the home who may provide us with a much more objective view of our relationships.

Out of a deeper understanding of the individual differences among children, parents can help children to develop the unique capacities they possess. Rather than being predominantly concerned with what the child can't do, parents can emphasize what he *can* do. With this emphasis we return to the importance of hope. Hope for the future must be placed in

terms of positive achievement; it cannot be built on a psychology of defeat and despair. Emotions are contagious; a parent's feelings of defeat and despair are all too readily communicated to the child. The child cannot have high expectations when these are not shared by parents.

### **Self-Understanding by Sharing**

Perhaps the greatest opportunities for parents to improve self-understanding arises from the sharing of experiences. Discussions of experiences and problems with other parents of handicapped children provide an opportunity for increasing the depth of understanding of problems. Physician parents of handicapped children with much knowledge of the handicapping condition of the child have often related how much help and support they have received from other parents. As a matter of fact, all physicians can learn from parents if they will afford themselves the inexpensive luxury of being good listeners. There is much the professional can learn from ordinary, everyday incidents. In this connection the story related by a mother of a preschool deaf child at an institute for mothers is worth retelling. She had a large farm family. A considerable amount of washing and ironing had to be done each week. One day as she was about to start ironing one of the children proposed that they have a garden tea party. To this she acquiesced.

Just as they were in the midst of having a delightful time, Mrs. Smith's mother dropped in. The mother noted the large ironing to be done and told the daughter that she could be using her time to better advantage. Mrs. Smith thought about it for a moment but replied that "the children would probably never remember whether the washing had been done that week, but they would never forget the tea party." The overtones and undertones of this story had great meaning for parents and professional staff alike.

A few words of caution are in order however. Occasionally, parents in their devotion to group activities may find an outlet for their problems at the expense of the child. The central focus of energies and activities of parents must be the child, lest the child feel that his care has been relegated to a secondary position. Unfortunately, no one can provide the energy and understanding of which natural parents are capable. Children should, therefore, not need to settle for care which is second best.

The healthy sharing of experiences, supplemented by the sharing with professionally qualified people as indicated earlier results in ever increasing depth of understanding by parents. Out of such understanding emerges a more comfortable relationship which helps the child to attain his fullest potentialities. Parents who provide such understanding achieve gratifications which cannot be duplicated.

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## **Applications for Grants in Cancer Research**

Acting for the American Cancer Society, the National Research Council's Committee on Growth is accepting applications for grants-in-aid for cancer research in the United States. Applications received before October 1 will be considered during the winter, and grants recommended at that time become effective on July 1, 1955. Investigators now receiving support will be notified individually regarding their application for renewal.

The scope of the research program is broad and includes, in addition to clinical investigations on cancer, fundamental studies in the fields of cellular physiology, morphogenesis, genetics, virology, biochemistry, metabolism, nutrition, cytochemistry, physics, radiobiology, chemotherapy, endocrinology, and environmental cancer.

Application blanks and additional information may be obtained from the Executive Secretary, Committee on Growth, National Research Council, 2101 Constitution Avenue, NW., Washington 25, D. C. D. C.