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A TREATISE ON CHILDREN WITH IMPERFECTIONS

"Know you what it is to be a child?...
It is to believe in love, to believe in
loveliness, to believe in belief; it is
to be so little that the elves can reach
to whisper in your ear; it is to turn
pumpkins into coaches and mice into
horses, lowness into loftiness, and nothing
into everything, for each child has its
fairy godmother in its soul." -- Shelley

What is it like to be born with a handicap? How and when does the child become aware of his defect? How are his interactions with others affected by his imperfections? What image of himself does he develop?

Improved control of infectious diseases by public health measures, immunization and antibiotics, has freed the pediatrician to devote time and thought to the growth and development of the young and the deviations from the norm. The advancement in the basic sciences of genetics and chemistry has enhanced his understanding of abnormal patterns of development. The continued study of the structure, function and inter-reactions of the whole organism on the one hand, and the ultra-microscopic nature of the substance of which that organism is constituted on the other, has the potential to initiate a new and enlightening era in pediatrics.

Intimate work with both children well-formed and those with flaws and defects in design has afforded opportunities to note similarities and differences.

CHILDREN WITH IMPERFECTIONS

Introduction

In the Beginning - - - - -

In 1952 a telethon sponsored by the parents of children with Cerebral Palsy netted a surprisingly large sum of money. As a result, a meeting was called in San Francisco to discuss the development of programs for cerebral palsy victims. As chief of the Department of Pediatrics of Children's Hospital, I was invited to the meeting. In preparation for the meeting I discussed with the director of physiotherapy the local unmet needs in the field of Cerebral Palsy. Her immediate response was "for the children under three years". In ____ a law was passed in California making funds available for help to children with cerebral palsy from birth to 21 years. The funds were allocated to the Department of Education to develop total programs within school systems to care for the children. In San Francisco, a school for children with handicaps antedated the new law by many years. The major difference between the proposals of the new law and the organization of services in the "Sunshine" school in San Francisco was that the latter provided for therapy through the Department of Health instead of through the Educational Division. Children were eligible

for admission to the school at three years of age. This left the pre-nursery school child without therapy. In the newer setup, the physiotherapy was provided in the school clinic regardless of the age of the child.

At the above mentioned meeting in San Francisco, I was alerted prior to the discussion that an effort would be made to have the program for infants and young children at Children's Hospital. The city at that time had two Medical Schools, and a neutral as well as non-sectarian place such as Children's Hospital seemed desirable.

The news of this choice was in the papers before there was any chance to consult with the Hospital Board, Administration or Staff. As sometimes happens, unfortunately, this publicity made it somewhat difficult for the program to get off to a smooth start.

The Department of Pediatrics was well prepared to launch a pre-nursery school service for handicapped children. For several years a weekly seminar on childhood ecology had made the staff not only knowledgable about normal growth and development but also acquainted it with the facilities for children in the community. An additional advantage was my experience with rehabilitation services in Veterans' Administration Hospitals, to which I had been Areal Consultant since World War II. It was not difficult to adapt the

knowledge and experiance gained in the Veterans' Administration to the young handicapped child. As a special preparation, Dr. Rusk's program at Columbia University was visited, and a day was also spent at the John Tracy Clinic in Los Angeles. It was Mrs. Tracy who gave me the courage to start "now". Her words were to the effect,-- Get a toe in the door and start; you will learn best by doing. The years of experience have shown the wisdom of that statement.

The school opened August 1, 1952. Space was made available in the main room of the Physiotherapy Department by shifting the patients usually seen there to other times and other rooms for two afternoons a week. The director of physiotherapy and the director of occupational therapy assumed responsibility for the work with the patients. The executive secretary of United Cerebral Palsy made her headquarters in the Hospital. Her skill and devotion to the program and to the Hospital for the short time she was secretary added immeasurably to the beginnings. It was a united, close-knit staff that launched the program.

Organizations, national in scope, are prone to have somewhat rigid regulations. Before opening, it was requested that in a disease as ill-defined as Cerebral Palsy, a rigid diagnosis in early infancy not be demanded; that the upper limit of age not be rigidly set at three years

but transfer to a public school be left to the discretion of the staffs of the involved programs, and at least until neighboring counties had time to develop their own programs county lines not be stringently enforced.

The demands for the type of service offered were surprisingly great from the start. The program from the beginning was designed to be a habilitation service for all children in need of such help. It was not set up as a medical facility only, nor was it set up within the framework of the traditional out patient clinic subject to eligibility requirements. It was open to all doctors and medical facilities for referral of patients in need of the type of program offered.

Not long after the launching of the nursery school, the Crippled Children's Service of the State authorized a neurological diagnostic clinic to the Center. In order to accomodate children not strictly cerebral palsy, the Little Jim Club, a hospital auxiliary, was asked for and it contributed a supplementary fund to the program. Since children with many types of deviations from the normal were admitted, the name was changed to the Child Development Center. In 1961 the first grant was received from the National Foundation -- March of Dimes -- to open a Birth Defect Center as a part of the services. This move was particularly appropriate because Children's Hospital had been a center for poliomyelitis and the staff had worked intimately with the Foundation since its origin. The rapid increase in volume

of work since 1961 attests to the need for services of the type given in the Center for children with imperfections and to their parents.

The basic organization of the Center was patterned after the rehabilitation services for adults already in existence, the Veterans' Hospitals, and from the John Tracy Clinic already referred to. Dr. Howard Rusk's Center at Columbia Presbyterian, the Clinic for Mental Retardation at Flowers Hospital in New York and the out patient services at Cornell Medical Center were visited and the personnel in these centers supplied helpful information. The probable reason that the organization has changed so slightly from the original plan is the a priori work done.

The Center is a multi-purpose center providing medical diagnosis, total evaluation of the child, diversified therapy to meet the medical needs and a variety of sensory handicaps, family counselling, follow through therapy, repeated re-evaluations and follow-up studies.

The medical staff has a pediatrician in charge and as many pediatric assistants as the volume of work dictates. The pediatricians have a complete panel of medical consultants available, namely, neurologist, neurosurgeon, orthopedist, ophthalmologist, otologist, pediatric surgeon, plastic surgeon, psychiatrist, dentist. A physiatrist supervises the work of

the physio-therapist and the occupational therapist. The laboratories of the hospital are equipped to carry out all necessary procedures.

The non-medical staff members are a nursery school educator who has general charge of the nursery school and individual educational evaluations, the social workers who perform a superb service with the parents and the personnel in the community agencies, the psychologists who are specially trained in child development and the tests appropriate for children with various sensory deficits and physical handicaps. The psychologists are also available for counselling. The other members of the staff are the physio-therapist, the educators for reading, and the secretaries.

There is no rigidity about the procedure of study but in general it takes a process as here described. A patient is referred by a physician or Medical Clinic. The patient is seen first by a pediatrician and the standard pediatric work up is performed. This part of the study includes such laboratory examinations as are indicated by the medical findings, X-rays, EEG, Clc, urine, chemistries, metabolic tests and chromosome studies. When the findings call for medical consultants a series of these appointments are arranged. Necessary medical treatments and surgical procedures are carried out.

Either following or interspersed with medical examinations are the studies by the other professionals, such as psychological examination, speech and hearing

evaluations, educational and social studies. Various therapies may also be carried on even while other diagnostic studies are being pursued.

There is plenty of opportunity for inter-communication between staff members and in a high percentage of cases a large conference is held when the studies are completed to which the referring physician and community personnel involved in the problem, educators, social workers, visiting nurses and sometimes government and legal representatives are invited. The study and conferences result in a long term carefully planned program of therapy, counselling and follow through with frequent re-evaluations in part or in total as indicated.

It should be recognized that with the many different types of patients seen, the study and programming varies greatly with each child. Some children who come in have been carefully worked up and are admitted directly to therapy; others are referred in from a distance for a complete diagnostic study, and when completed therapy must be sought in the local community.

The nursery school is conducted five mornings a week from 9 to 11:30. Each session is limited to ten children. Some children come once a week, some two or three times, and some five mornings. The time spent in the nursery school is decided by the therapy team, the nursery school teacher being in charge. A fragile, young child of two years may tolerate

only an hour in the group. The child may be placed there while the mother talks to the social worker. The nursery school serves both for therapy and for observation. The therapy aims to prepare the child for the next learning experience. Those with major orthopedic handicaps are eligible for public school special education at three years of age. The Department of Education also has a school for the deaf, one for the severely retarded and special classes for other types of handicaps.

During the afternoons, there are two days of sessions for speech stimulation of young children, two afternoons for educational evaluation and work with pre-nursery school children, and one afternoon for a follow up joint medical and non-medical clinic.

The psychologist, speech audiologist, social worker and physician carry on work by appointment simultaneously with the above activities.

Although the structure of the program in the Center has been modified only slightly, the philosophy and concept of the staff have changed considerably with the years of experience. The staff has been stable; the few changes that have been made have not been disruptive as new members have been selected with care and interviewed by all the members of the staff. The focus has always been on the child and his family; this leaves little time or thought to inter-personal staff discords. There is no hesitancy in answering a mother's question by saying, "The social

worker can be of greater help to you in answering that question"; or,"Let's ask the doctor to answer your question."

In the next division an attempt is made to portray the problems of children with handicaps, of their parents, of siblings, of neighborhoods and the community as viewed after a dozen years of experience.

Our Children

"Children's griefs are little, certainly;
but so is the child, so is its endurance,
so is its field of vision, while its nervous
impressionability is keener than ours."
-- Shelley

It may be startling but it is not improper to think in terms of human design. Anthropologists have studied the physical characteristics and types of mankind. (5) Animal breeders and fanciers are very aware of perfection both of form and of function. The mental image of good design in children has evolved subtly from probing into the possible etiologies of the abnormally developed child. This image of good design becomes the background for analyzing those born with abnormalities or acquiring injury during the growing phase.

Unfortunately, the constant addition of new knowledge in the sciences has crowded embryology into the college or pre-medical courses. Furthermore, the basic study of medicine is done on the adult with the consequence that the child, by most medical specialists and even by some pediatricians, is considered a miniature adult and treated as such. This is reminiscent of the early scientists who first looked at the ovum under the microscope and anticipated viewing a miniature human figure. (6) Development is by design. The blueprint is formulated very early indeed, and the pattern is

diligently followed. It may be faulty, however, and it may be altered.

Those individuals with abnormal chromosomes we now know have a special pattern that in many instances is readily recognizable. These syndromes were described long before chromosomes were counted. Into this category fall the syndromes which have been labeled in textbooks as Klinefelter's, Turner's and Downs', named after the physicians who first described the entities. Although such names will persist for a long period of time as rather weird memorials to these men, the modern numerically oriented age undoubtedly will prefer a name such as Trisomy 21. There are other syndromes due to faulty chemistries or enzymes and the list of these is growing rapidly. In this latter category are the phenylketonurias, aminoacidurias and galactosemias. It is fairly easy with the new laboratory methods to screen the individuals for the larger classifications. Most of the children in the above categories have telltale stigma when looked for. There are primitive hand markings, crooked fingers, overlapping toes, webbed digits, oddly shaped or low set ears, too widely or too narrowly set eyes, peculiar hairlines, abnormal teeth, high narrow palates, Kayser-Fleischer rings and innumerable other little giveaway signs, -- signs which bring to mind phrenology and palmistry.

The child who has suffered insult in foetal life may present a variety of symptoms depending on the type, duration

and timing of the injury as well as on the original design of the foetus. The end result may be severe malformations as the picture seen after rubella in early pregnancy. The newborn then may be blind, deaf, retarded and have gross muscular disabilities. On the other hand, the effect may be as subtle as dyslexia, an inability to learn to read, an abnormality which may go unrecognized until school age.

The effects of foetal injuries at term again will vary with the severity, duration of the insult and with the stamina of the foetus. A well designed infant with a good pregnancy record may withstand hypoxia or trauma at birth remarkably well. A poorly designed, or stunted foetus, may succumb to the same type of stress. An infant born normal who is injured after birth, for instance a child who suffers a skull fracture early in life, even if severely retarded as a result of the injury, can be recognized as being different from the child with multiple stigmata. Similarly, a child with blood incompatability may proceed with normal development through the foetal period and then sustain injury from hyperbilirubinemia. Such children present a picture that is different from that of the child of poor original design.

Children are also seen with post-encephalitic and post-meningitic syndromes. No child is necessarily immune to these infectious diseases. The correct interpretation of the child's abnormalities usually can be arrived at by the history combined with the physical examination and total evaluation

of the child.

When a foetus suffers injury from any source, it must be assumed that to some degree the entire organism is affected. This does not preclude major pathology in some particular organ. This we know depends upon the timing of the insult in relation to a particularly rapid growth phase. At times, more than one anomaly will help to date the time of the insult.

In a study of children with defects, (7) it was found that 70 percent were on or below the 3 percentile in height and weight. This type of total stunting of an organism has been demonstrated in chicks subjected to a teratogenic agent. The chicks not only have anomalies but they are small, fragile, and have a shortened life span. This stunting is basic and cannot be attributed, as it sometimes has been, solely to poor appetites, difficulty in eating, and neglect.

The effect of the injury on the whole organism is also apparent in the multiplicity of abnormalities. The commonly encountered associated defects are visual, hearing, speech, dyslexia, perceptual problems and deficiencies in discrimination and judgment. Even with normal intelligence the children have difficulty in acquiring the proficiencies of their well-designed counterparts.

In the more subtle abnormalities, often the result of slight hypoxia before or at birth, the child gives the impression that the "finishing touches" have been omitted. He often has mixed dominance or is left-handed. His motor coordination is poor, his attention span is short. He may tend to perseverate, and he frequently has difficulties with communication, either oral or written. (8)

Even when growth has been interfered with seriously, the developmental pattern tends to follow the same chronological order as the normal. It is therefore essential that therapists and diagnosticians know the normal pattern of physical, mental and emotional growth.

When working daily with children who are blind, deaf, lame, grotesque or retarded, it is the child behind the handicap that emerges, and the likeness of this child to all other children places the imperfections in a new perspective. As has been rightly said, we are all a little queer. When this is recognized it is easier to view with equanimity those with greater deviations or imperfections and relate or interact to the personality of the individual regardless of the form in which he dwells.

The child trapped in the most uncomfortable body enjoys the experience of new sights, new sounds, new touch. These experiences can be brought to him. Like normal children, the handicapped child likes to splash in water, and to dab with

finger paint. The child who has been unable to crawl or walk until two or three years of age goes through his exploratory phase late; he may go through it faster and with more sophistication, but he has his fling at it. Even the most handicapped child, at the appropriate developmental stage, will show curiosity and explore his ideas of sex,-- why are there girls and boys,-- and in his own way reach some conclusion regarding the future role of girls and boys as mamas and papas. A severely retarded girl, at eleven years, began to ask the questions regarding the roles of boys and girls and mamas and papas that are ordinarily the concern and curiosity of children between three and five years.

Like normal children, the handicapped children often have a fine sense of humor, they will be impish, and they can have tremendous motivation, persistence and curiosity.

They form deep and lasting attachments to each other. Michael, a boy of eight years, a severe rigid athetoid from kernicterus, after transfer to a State Hospital developed an affection for a hydrocephalic boy in the adjacent bed. Both were confined to their beds, neither could speak. Muscle control was so poor that hand communication was impossible. They showed deep concern when separated, and were happy when brought together again. The personnel in charge recognized and honored the attachment and the boys were content. David,

age four years, with a severe quadriplegia and without speech, formed a deep and protective concern for a severely handicapped little girl in the nursery school. Susan, among other things, had difficulty in balancing her head, and in spite of his own severe communication problem he would call the attendant's attention to her when she got into an uncomfortable position. He would not go outdoors to play unless she was brought out also, and he did not wish to leave the nursery until the girl's mother called for her.

Illegitimate abandoned twins were picked up by the Protective Society at the age of two years. Penny, as a result of a subdural hematoma, is severely retarded. Patsy has an I.Q. of between sixty and seventy. Neither girl walked until over two and one half years of age. Early they were in a foster home with three other handicapped girls. They attended our nursery school until they were transferred to the School for the Handicapped. The foster mother was a sensitive, loving person and the children were happy. The foster mother died suddenly and unexpectedly. The children in her home were scattered and Penny was placed in a state institution. The foster children who remained in homes in the city continued to be followed at the Child Development Center. After five or six years, when the girls had reached the age of eleven years, Patsy who was still in the community, when visiting the Center asked me, "Who was born first, me or my sister?" This question was readily answered. Her next

question was, "Will I ever see my sister again? I miss her so much." Arrangements were made for her to see movies of herself and her sister taken when they were both in the Nursery School. Patsy requested that these be re-run five or six times. Later it was arranged for the foster mother to take her to call on Penny in the State Hospital. On her next visit to the Center she said, "Some day I want to take care of Penny myself." Patsy is in an ungraded class in school. At the foster home she is very much liked; she is gentle, kind and helpful. She is somewhat lacking in judgment and discrimination. Her academic achievement is below normal.

These children, like their normal counterparts, are sensitive to the adults about them. Good and bad days coincide with the mood of the mother. When she is tired and discouraged the child does not perform well. Acceptance by a staff of workers tides the children over such periods. When leaving the surgical ward after visiting a child in casts, the physician heard her say to the other children, "She loves me."

Many parents have said that the Nursery School program has helped them more than the children. The longer one works intimately with these little tots, the more certain one becomes that the experience is also very helpful to the children. To them is brought the experience that normal children seek and discover on their own. They learn the feel of running water,

they dip their hands in paint and smear it; they wander, in wheel chairs, on crutches or on tricycles, over to the laundry, to the engine rooms and up to the cafeteria line. They are taken to the zoo; they ride on the merry-go-round. They listen to music; they celebrate holidays. They are accepted by many adults, their staff and other children's parents. Even those who it is later found necessary to place in state institutions are more relaxed and happier. Their early experience has been a help to them. They should not be denied this bit of happy memory of babyhood. Many severely handicapped children have long memories.

The less severely handicapped child, the one that parents and teachers do not want to set apart but want to integrate into the normal group, sometimes suffers more emotionally than does the one with greater defects. Adults forget how sad and humiliating it can be to a five-year-old not to be able to hop; or a six-year-old in the first grade, to be baffled by words and numbers when the rest find learning to read an enchanting experience; or to have a classmate query, "What is wrong with your arm? Why can't you catch a ball?" Children who have been happy, smiling, roguish nursery tots come back sober with hurt, grave little faces.

When does a child become aware that he is handicapped or different? This varies with the child, his intelligence, and

sometimes with the types of exposure to information. Michelle, at four and a half years, while watching a Cerebral Palsy program on television, turned to her mother and said, "I am handicapped." Michael, not more than four years of age, was able to make many sounds but had no real speech; suddenly, one day he appeared to realize that what he was attempting to say was not understandable. Robert, at seven years of age, came home from school one day and asked his mother, "Have I had polio? Is that why I can't use my arm?" We forget that children are born with potential but not with knowledge. Information is acquired. The person who has been whole, who has had speech or who has had vision and loses it, is very different because of the experience he has had, from the child born with an amputated arm, or born deaf or blind. Also, as in all other areas of learning, total comprehension is slowly acquired. Parents of normal children use a Spock (9), a Holt (10), or a Gesell (11) reference book. We have no similar studies on children with defects. It is often said of normal children, "They are so cruel to a child who is different." Children are not cruel. They lack experience; they are often thoughtless, but more often they are embarrassed by a difficult situation, and to deal with it react with laughter, teasing or ridicule. It is not uncommon to see adults react similarly.

Children are direct and fair. An explanation by an understanding adult quickly reveals the child's eagerness to

be helpful and kind. Parents, teachers, and neighbors need to appreciate this. Robert's mother replied to his question about polio by saying, "No, you did not have polio, but you had a disease very much like it and it left your arm weak." Then she added, "It won't get any worse, and you know how many things you can already do with it." The nursery school teacher recognized Michael's dilema when he discovered he was not using speech, and reassured him by saying, "Michael, your speech is not yet clear, but you can help us by pointing to what you want." It must always be assumed that a child takes in much more than he can give out.

How do you answer the child who says, "Mother, why did you born me this way?" The child who is born with or has suffered injury to the brain will almost always deviate from the normal in some learning process. Some of these variations are extremely difficult to understand, and hence to teach to others. Color-blindness, for instance, is fairly easily understood because black and white and color are everyday experiences. It is not uncommon to know that a person who has suffered a stroke may have difficulty with speech or with memory for names of familiar objects and these have to be re-learned. Experiences like these help us to understand the child with aphasia or the child with word blindness. An American Indian father of a dyslectic boy said, "I can't read either; all those little crooks look alike to me." To a Westerner, Chinese characters all tend to look alike, too.

There are children with even more difficult visual perceptual problems. A perceptive teacher noted that Pamela recognized her teacher and classmates in the schoolroom, but when she encountered them in new or strange places she might ask to be introduced to them. Experiences with individuals who have these problems are disconcerting and to the novice can be very disturbing. It is not surprising that these misunderstood children either get angry and act out, or else get discouraged and withdraw. Even more simple problems in learning will greatly disturb a child and unless he receives help early he will show emotional scars from the experience. Truancy from school is one of the first overt acts. This again may be followed either by acting out, which may lead the child into delinquency or crime, or by withdrawing and becoming a neurotic or even a psychotic individual.

Fortunately, at ten or twelve years of age, children begin some self analysis as well as some analysis of parents and other adults. Frequently at this age, the handicapped child will gain control of his impulses and show marked improvement. This is particularly true of the hyperkinetic child. A child who has been considered rather incapable may suddenly begin to organize his behavior and function better than anticipated. Other children may have greater difficulty when adolescence approaches. David had a mild athetosis and a moderate hearing loss as a result of kernicterus. He tested

above average in intelligence; he was well liked by his playmates. He had his own paper route. His mother described him as a reliable child. At fourteen years of age his school work began to deteriorate; he usually forgot his hearing aid, and he repeatedly failed to appear for speech therapy. A staff discussion brought out the possibility that this boy was withdrawing in this manner because of his fear or dread of assuming adulthood with a severe handicap. Adolescent counseling was recommended.

Adolescence poses other problems for both parents and the child. A frequent concomitant with any lesser degree of injury to the brain is a lack of discrimination and poor judgment. The retarded girl who has felt slighted and rejected and who is starved for affection, with her lack of judgment, is very prone to get into serious difficulty. The boy in the same situation may be unable to deal with his adolescent drives and may get enmeshed in situations beyond his control which in turn may involve him in misdemeanors or even serious crimes. Our handicapped children should be supervised and carefully counseled through this period of development. For the adolescent supervised homes may be necessary. With maturation, certain individuals may again be members at large in society. There are many who should have some type of partial guardianship or some "Big Brother" relationship throughout life. It would seem that this function might be assumed in part by the churches.

There is a large group of children, some estimate it as high as twenty percent, who function marginally for a variety of reasons; they may be emotionally disturbed, culturally deprived, neurologically handicapped, crippled, or have a borderline I.Q. They are unhappy, frustrated, confused. They have a poor image of themselves. They constitute the raw material, the great reservoir from which come delinquents, neurotics and just inadequate citizens. They are a salvagable group. Our communities fail them.

The Parents

"...the poets feign the miserable mother, Niobe, (overwhelmed with her losses) to be at last transformed into a rock, thereby to express that melancholic, dumb and deaf stupefaction, which benumbs all our faculties, when oppressed with accidents greater than we are able to bear." -- Essay on Sorrow -- Montaigne

"I never yet saw that father, but let his son be ever so decrepit or deformed, would not, notwithstanding, own him." -- Of the Education of Our Children -- Montaigne

What is it like to be the parent of a handicapped child? How does a parent accept an infant with defects? What do parents feel when they are told, "Your child is a Mongol", or has "cerebral palsy" or has "hydrocephalus"? The birth of a defective child may occur in any family. It is not limited to any class, color, creed or intellectual attainment. The birth of a handicapped child is a sad event. It is a grief that continues.

The birth of a defective child causes a bereavement (12) that in many respects is deeper and more difficult to deal with than mourning for a dead child. It is a mourning for the child that had been anticipated, confounded by the living presence of a small defective substitute not responsible for his own deficiency. As one mother said, with sobs, "We have nothing to talk about; when we meet our friends we don't know what to say, so we stay home." She then asked, "Do other parents feel this way?" These feelings are followed by feelings of guilt on the one hand and overwhelming compassion for the little defective infant, the cause of it all, on the other.

People differ in their capacity and their methods to deal with the problem. The strength, not the frailties, of parents is a recurring amazement to the staff.

A family with three normal boys lost a child with a hereditary degenerative disease at the age of seven months. A little girl was born a year or two later, and shortly after birth it was recognized that she,too, was a victim of the disease. She grew and progressed fairly well the first twelve to eighteen months, and then the slow deteriorating process began. She survived to the age of four years. She was cared for in the home, which was the parents' choice, and there she died. The parents had been instructed that the hospital would accept the child at any time. For several months before her death

she was fed by tube. She had to be suctioned frequently; a practical nurse was placed in the home to assist the parents. After death the body was brought to the hospital for autopsy. Some days later the mother stated, "She died as we wanted her to die, on a bright Sunday afternoon, at home, with her family at her bedside."

In another family, twins were born, one of which was still-born and the other had convulsions in the nursery. Johnnie, the surviving child, had microcephaly, quadriplegia, and was severely retarded. John was brought to our activity regularly, the parents participating actively. When he was four years of age, the home was opened for boarding other handicapped children. For two or three years five Mongols were cared for in the home. Then a normal baby girl arrived and their own severely retarded child as well as the foster children were placed in a state hospital. This family deserves to enjoy their normal little girl.

There are other types of parents. We have children who are handicapped because of parental abuse and battering. (13) In most instances, when this has been encountered the parents themselves have been defective and should have been under guardianship. It is an inconsistency to follow the performance of trainable retarded children through school, to place them in special classes for educable and trainable, to

test them and record that they lack judgment and discrimination, and then at eighteen years of age turn them out to seek their own place in a competitive world. When they fail, we prosecute them for their crimes.

We have had parents who, when the records of the various agencies that had served the family were amassed, it formed a formidable pile going back sometimes two or three generations. One mother with such a family record, after bringing a defective child to the nursery for a period of time and mingling with the other mothers, said, "This is the first time I have been treated like a human being!" Social rehabilitation is possible.

There are also parents who have deep feelings of guilt that are not revealed for several years; a mother who has given away a fine though illegitimate baby later has a premature severely handicapped child in marriage, or the mother who has an illegitimate defective infant during her marriage. The fact that these guilt feelings finally can be shared is significant and represents therapy.

There are parents who after several years of caring for a mentally retarded child at home, during which time they have been active in work with organizations for the handicapped or retarded, then place their child in an institution and drop all contact with their former intimate associates. There are other parents who have accepted the advice, probably too

readily, and too often of their physician, to "put him away". They put him away and work feverishly thereafter in all types of organizations dealing with the handicapped as if they were desperately trying to compensate for feelings of conflict.

A severely handicapped child born to a family causes grief. There is no way of "putting it away". The fact remains and the child remains. Parents must make their own decisions regarding the how and where their child is to be cared for. Professional people can counsel and give support. If families are given time, a chance to talk, to think, to exchange experiences with other parents and a chance to ask questions of medical advisors and other professional personnel, a decision without regrets can be reached. A mother is not the only one concerned about a handicapped child. A father is a parent also. A father's pride and joy in his offspring is equal to that of a mother's. A father's sorrow and grief over a handicapped child is as real as is that of a mother. A father usually has the respite away from the home during working hours. It is the mother's around-the-clock chore that wears the mother down often before the father. It is the mother also who has the most contact with the physicians and she is better informed about the child's true status. She usually comes to the realization of the chronicity of the condition and accepts it before the father. Many a father has sat with one of our staff members with his severely handicapped child and wept bitterly over the

necessity of placing the child outside the home. Often a father has stated he must do it because of his wife's inability to continue to cope with the problem in the home.

between parents of handicapped children

Divorce is probably as common but not more so than in the population at large. Sometimes the mother devotes her time to the handicapped child to the exclusion of all others in the home. This reaction is usually an exagerated manifestation of an already existing withdrawal from the husband and home responsibilities. A divorce, therefore, may only be accelerated. At other times, a faltering marriage may be strengthened as parents face the reality and assume responsibility. The adjustments depend largely upon the parents' ability to assume adult responsibility for the task ahead. Many physicians undoubtedly give the advice to put a child with severe defects away on the basis of their own unresolved conflicts regarding the retarded and defective.

The Siblings

"Am I my brother's keeper?" --
The Bible

What is it like to have a sister or brother who has defects, who may be retarded or even grotesque? What do you feel toward him? Does it tend to make you love more, hate more or fear more?

Children have long memories. Traumas are also recorded in the subconscious. Children are exceedingly sensitive to and perceptive of parents' feelings. The reaction of siblings to a handicapped child in their midst is a reflection of the parents' attitudes. Nowhere is the old saying more true than in a child's learning from his parents, "What you are speaks so loud, I cannot hear what you say."

In one family a Mongol was born, the sixth child, the oldest sibling being sixteen years. Upon the advice of doctors and hospital attendants, the parents placed the baby in an infants' home. At the end of a six months period, when the foster home folded, the family had a conference to discuss the fate of the sibling Mongol. It was unanimously agreed that he would come home. When the sixteen year old daughter was asked how she would feel about bringing her boy friends into her home, her rather sophisticated reply was, "How do I know that I will not have one? Isn't it better to find out a boy's attitude in advance?" Children are direct; unfortunately, they learn to be devious.

The pressures and the physical labor connected with a handicapped child can be very great. No woman can nurse a disabled child day and night with no relief in sight without injuring herself and without affecting other relationships in the home, leaving the home showing the effects. As noted earlier, fathers get a break while away at work.

There is only so much time and a mother has only so much to give to a family. If the pressures become too great, the siblings may suffer.

Children vary in the sensitivity with which they are endowed and, like a parent, one sibling may reach the limit of tolerance before the others do. There are other circumstances that make it desirable to remove the defective child, or children, at least temporarily from the home. The Frolton's had two retarded girls between a normal older girl and a younger boy. Nancy, at eleven, was a benign child with an I.Q. under fifty who posed no great problem in the home, but Ethel, age eight years, was aggressive and hostile toward her little brother. To the Center staff, this family of children posed such a formidable environment for the little boy that it seemed necessary to place the retarded girls temporarily away from home. The situation created a background too abnormal for a child's early healthy development.

Older retarded children have a need for being with their own kind. Many of these problems can be eased by the community sharing responsibility for the care of the children with defects.

The Community

"People need to believe that man will sacrifice for man, that he is willing to walk the wide earth in the service of man." -- Dr. Schweitzer of Lambarene -- Norman Cousins

How have communities met the needs of children with defects? In a nation of plenty do we care for our handicapped individuals in a manner appropriate to advances in other areas? May emerging countries learn from our mistakes and develop superior systems for meeting the needs of all strata of society to those we have? Do we need to change our methods?

The story of the growth of welfare work in our country has not yet been written. It will be difficult to write. In a nation of free enterprise and plenty, the dichotomy between self-aggrandizement and provision for the needy has certainly had a zig-zag course. A description of community resources and the work they do, both public and private, is impressive, but when help for a particular child with one or more problems is sought, the resources are often lacking.

The Child Development Center started around the pre-nursery school child. It was decided, however, that the children would be followed after they left the activity by having them return to the medical clinic routinely. The entire staff attends these follow-up clinic sessions, and the

social worker, educator, psychologist, physiotherapist and occupational therapist are available to answer questions, each in his own field. This means that the entire staff has maintained contact with the patients. An "open door" policy has been practised and former patients feel free to talk over problems with staff personnel at any time.

As the program has evolved and a greater number of children of school age and beyond are served, the deficiencies in the community have become more and more apparent. The child with a defect does not have only one problem; he may be a deaf child with cerebral palsy, a hyperkinetic child slightly retarded, a superior child with dyslexia, and all the children quickly develop some degree of emotional disturbance. Furthermore, families have worries ranging from economic difficulties to deaths and suicides.

This country provides many services for its children. The handicapped have not been forgotten in this planning. Presidents, legislators, humanitarians and parents have sought and obtained services for the children with defects. At the state level the Department of Public Health has a Crippled Children's program and a Maternal and Child Health Division. There is a Department of Mental Hygiene which is concerned with the emotional health of the citizens young and old, retarded and intellectually normal. The Department of Education has a special division devoted to the training of the handicapped and retarded children.

In addition, there is a rehabilitation program for those with defects, and a Public Welfare Department for those in economic need. These are public, tax supported programs; the private charities are numerous, more than one for every day of the year, ranging in interest from cancer to cystic fibrosis, and in slogans from Christmas stamps through valentine hearts to Easter seals.

With all this available, the tragic lesson has to be learned that the needs of the children and the provisions in the community do not dovetail. The services provided appear as circumscribed little islands with defined limits; the deaf school cannot take a child with cerebral palsy; the cerebral palsy school cannot take a deaf child; the superior child with dyslexia is placed in the retarded group because his reading problem lowers his score; the hyperkinetic child with a neurological deficit is placed with the emotionally disturbed even though he requires a carefully structured environment and the latter great permissiveness.

The staff worker, child in hand, knocks vainly at one door after another without finding a suitable placement. The community services are categorized to an extreme degree; unfortunately, children do not come in pure categories, they are checkered and not divisible.

Joint Attack on Community Problems

As long as we have children born with imperfections the children will have multiple problems. This situation will not change. The community, however, can change. The focus of health and welfare activities must move from agency organizations and preoccupation to patients' needs and the solution of patients' personal problems.

The basic needs of children with handicaps are the same as those of normal children. These basic needs are home, medical care, education and training, recreation, and religion. Children need a home and the love and security that go with it. Children need medical care for the best development of their physical potential. Children need education and training to reach their best mental potential. Children need recreation. If all work and no play makes a normal Jack a dull boy, it makes the handicapped child an even duller boy. Children need religious experiences. Children need preparation for work.

How can a community reorganize its services to provide these basic needs for the handicapped children?

Homes and Housing

The first basic need mentioned for a child is that of a home. The infant and young handicapped child needs a home and parents. Any departure from this can scarcely ever be a perfect substitute.

There are instances when foster homes and nursing homes have to be used. These are never a true substitute. Such homes are not permanent. They may close their doors at any time for a variety of reasons. They usually specify the ages of children that they will take. Children do not remain at one age or size. It is just as traumatic to a handicapped child to be moved from one home to another as it is to a normal child.

There may come a time in the life of certain children when the home is not the best place. Children pass through stages in their development of independence. Under three years a child needs a mother very much. Between three and six years of age he tolerates separation with increasing ease but still needs frequent communication with his parents. From six to twelve or thirteen years of age, the handicapped like the normal may thrive in boarding schools where with close communication, are possible. week-ends and vacations with the family. During adolescence this tolerance of separation increases. In the case of a moderately to severely handicapped child, partial or temporary separation from the normal, with activities scaled more to his own abilities, may be a very welcome interlude for the child. If parents and siblings understand this, they may relax and also appreciate such interludes.

There is a definite need for boarding schools for a certain number of handicapped children, especially from the

age of ten up and through adolescence and young adulthood.

The teen age often is a troublesome period for normal children. The adolescent drives in children slightly retarded, and lacking in judgment, frequently get beyond the control of the family. A period in a boarding school, carefully supervised and especially designed to meet the needs of these children over a period of several years, can be very helpful. These children then may be able to assume life in the normal community. As an example, when the history of a foster child was obtained, it was learned that the mother had had a hemiplegia, convulsions, and aphasia at five years of age. At twenty-nine years of age she had been married and divorced with the child of that union given to the custody of the father. Since then she had had three illegitimate children; one of these died and two were in foster homes. When this mother was brought in for examination, she still had evidence of her hemiplegia, her speech was faulty and her judgment and discrimination deficient. Who is at fault when these things happen? Guidance into maturity might have prevented these tragedies for the girl.

When the school period is passed, another type of living arrangement for young adults without the possibility of living at home should be available. For the most severely retarded, small custodial institutions provided by the state,

the churches and privately endowed, are needed. It would be preferable to have several kinds rather than only state institutions. This would create better grounds for experimentation and innovations in learning, recreation, hobbies, etc. The religious institutions also might offer a type of opportunity for participation in work which would give satisfaction to many individuals that the private or public ones could not do.

Apart from the severely handicapped, there are a large number of individuals for whom life could be made easier and more gratifying if there were homes or apartments designed for easier living. Cars have been designed to make it possible for drivers to manage even with some major handicap. Private homes have been so designed, also. The big cities or urban communities might very well design apartments without entrance stairs, with elevators that take wheel chairs, with doorways that make ingress and egress simple, and with many other devices to facilitate mobility for the crippled.

There are some children who are so retarded that they are untrainable or they are so physically and mentally defective that they cannot be taken care of adequately in any home at any time in their lives. These are the most severely involved children in the state institutions. In recent years there has been grave concern directed toward the management of the problem of retardation by state institutions. The

amassing of large numbers of defectives in one area has many drawbacks. Frequently the institutions are isolated from medical centers and not easily available for study or for teaching of medical and other professional students. It is extremely difficult for parents and often for professional people to view large aggregations of defectives with equanimity. Decentralization with better facilities at local levels has been urged . One partial solution would be for the hospitals to assume greater responsibility for the children with severe physical problems. The need for hospitalization of normal children has decreased. Hospitals might consider, therefore, the establishment, after proper diagnosis, of minimal care areas for the patients who are so physically and mentally handicapped that they need bed care. This might be done by the state contracting with local hospitals for such care. This arrangement would place the children under the same professional personnel as the rest of the hospital patients; these children would then be available for teaching purposes as a part of the population in need of medical care. The parents, relatives, and friends could visit frequently, and the children could be taken home for periods of time.

The children somewhat less handicapped but still in need of total care should have hospital beds available for superimposed acute illnesses and also for a family crisis. This type of care also could be contracted for in existing

hospitals. These children might spend most of the time at home in contrast to the previously cited group in which the greater part of the time would be spent in the hospital.

For the children too severely mentally and/or physically handicapped to be in any school, but not in need of hospital care, there should be available nursing homes and/or day care centers. These should be under medical supervision rather than under the educational department as is now provided for by legislation, though not usually implemented. These children will profit more from the skills of the occupational therapists, physiotherapists and practical nurses than from educators. The latter should visit such homes on the same basis as they now do hospitalized children.

Medical Care

The second basic need of a handicapped child is medical care. This means first of all the routine medical attention that normal children receive. It covers nutrition, immunization, counseling and care of illness as it arises. A handicapped child needs more than the normal. The majority of these children are frail and more susceptible to acute diseases as well as prone to chronic conditions. Furthermore, a handicapped child is entitled to a careful medical study of his defects, and for periodic reevaluations.

Children born with defects may need the skills of almost any specialty or sub-specialty, in addition to pediatric care; i.e., the orthopedist, neurologist, neuro-surgeon, plastic surgeon, pediatric surgeon, ophthalmologist, otologist, endocrinologist, hematologist or psychiatrist.

It is essential that some physician is not only in charge of the child as a person but coordinates the sequence of the other medical repairs and treatments. The pediatrician is best qualified to assume this responsibility. In order to spare the patient and the parent, usually the mother, the hardship of travelling from office to office for care, a center in a hospital setting where the patient and doctors can meet is a logical development.

A child born with a major defect or acquiring one during his rapidly growing period needs more than a medical diagnosis. He needs a total assessment of his potential and a social diagnosis of the family and community in which he must live. Like the normal child, the one with a handicap continues to grow and develop; consequently, one examination and one assessment are not enough. Proper medical care requires regular examinations at intervals, re-assessment, counseling and placement. Facilities for such appraisal should be available to physicians in a facility not unlike the organization of a clinical laboratory with a pathologist in charge of a para-medical staff. A Child Development Center seems a

happier choice of name than habilitation or rehabilitation. Child Development indicates a study of the growth of a child with abnormalities against the known pattern of normal development.

A total assessment of the child should include:

A medical evaluation by the pediatrician, including the laboratory tests. The pediatrician should select the necessary medical consultants.

A psychological examination by a person trained in developmental psychology.

An educational evaluation, the extent of the latter depending on the age of the patient.

Hearing, speech and reading evaluations at the proper age levels.

A social diagnosis of the family and the community resources.

This type of assessment, in total or in part, should be repeated somewhat as well child examinations on normal children are done, -- frequently the first year, then at longer intervals as the child matures. Particular attention should be given to the periods of crisis, namely, at two to three years of age, when the normal child has acquired ambulation, self help in feeding, speech and toilet training; at five to seven years of age, when the acquisition of the three R's becomes important to the child; at thirteen to fourteen years of age,

or the beginning of adolescence. The child then establishes his own independence, and the handicapped child is faced with the additional apprehension regarding his ability to attain this status; and finally as a young adult seeking a job, a home, marriage and complete integration into the community.

This type of service to the handicapped and his family has proven to be exceedingly gratifying to the child himself, his family and to the staff.

Special mention should be made of the non-medical staff. It is difficult, time consuming and discouraging to work with defective children. There is so little feed-back. If a worker is isolated, and working alone with them, it leads to ennui. The hospital setting, group participation, contact with research activity, participation in education and communication inspire growth. This is the way new ideas are born. Educators, especially teachers in nursery schools and kindergartens, are trained observers of the young, and will detect the child with abnormal behavior or function quickly, but their skills are seldom utilized by either physicians, psychiatrists or psychologists. It is only in recent years that Child Development Centers using the personnel and techniques of all these specialties and disciplines have been established in Medical Centers. Even the centers in medical schools and hospitals frequently separate the children into clinics for the retarded, for the emotionally disturbed,

for cerebral palsy and for epilepsy. Habits are hard to break. Any child with either an anomaly of or an insult to the nervous system has some physical involvement, even if it is only incoordination of fine movements; he has a greater tendency to seizures if only recognizable in the electroencephalogram or behavior equivalents, and he almost invariably has some learning problem.

Education and Training

The third basic need of a handicapped child is education and training up to his best potential. One of the early discoveries in the work was that the children and the community resources did not dovetail.

Where lies the fault? No doubt in part it is a consequence of spontaneous growth in separate areas. The situation is not unlike that found in medicine when a new entity is discovered. The symptoms and signs are clearly defined, the syndrome is carefully delimited. Then follows reporting of similar cases from many areas; as knowledge of the condition increases greater variation is described and soon carrier states and frustrate forms are reported. Social structures similarly have been established to meet specific needs. They have been pressured into existence by parents, by humanitarians, by single individuals moved by personal experience. The purpose of each has been clearly defined and the limits of

the limits of service set. The time has come to widen our horizons. As long as there are children born imperfect, these children will have multiple problems, they will not come categorized. Agencies can be changed, the children will not. The focus must move away from the agency to the child, his family and environment, and the services altered accordingly.

In the infant and young child training and therapy are inseparable. Children with certain physical defects need therapy as soon as the handicap is recognized. Those with motor problems such as cerebral palsy should be started in infancy with physical therapy and occupational therapy. Deaf infants are now fitted with hearing aids and acquainted with sound stimulation as soon as the hearing loss is discovered; parents are taught to speak to them so that they early acquire lip and face reading. Blind infants can be helped by instruction to parents and attendants.

For the infants and pre-nursery school children, therefore, a hospital based program is preferable to either a school or a public health clinic. Physicians in practice are the first to be called upon when the parents become concerned. Physicians are accustomed to send a child to a hospital for further diagnosis. A center set up to assist them with the diagnosis and assessment of the child as noted earlier can be considered comparable to the clinical laboratories with a

pathologist in charge of a paramedical staff. Physicians will send a child to such a facility when they will not send him to a school or public health clinic.

There are other advantages to a hospital setting for the observation and treatment of infants and toddlers. This is the period in which the parents have the greatest number of questions; they need to have access to a facility that includes physicians readily available daily and all day long. This age period is also the time when it is most difficult to know or to predict the child's final status. It is equally important that the non-medical staff members have physicians available with whom they can discuss their observations and questions. The physicians also learn a great deal from the objective and experienced observations of skilled non-medical personnel in other disciplines.

Between three and four years of age children, except the severely handicapped, should be ready for transferal to public special classes, where their training can be continued. Even the retarded ambulatory children should be in nursery schools or the equivalent of a kindergarten between ages three or four years and eight years. It is a grave error to leave these children without training and without experienced help until the age of eight years. Children beyond three or four years of age with two or more major handicaps should have available facilities for therapy of both

handicaps. This may be done either by having school facilities so grouped that therapy is provided in a central place on the school grounds, or by providing transportation from the school to the hospital facility. The day then would be divided between academic classes and a habilitation program.

The remaining children, whether physically handicapped, retarded, emotionally disturbed, blind, deaf, aphasic, dyslexic or hyperkinetic, can be and should be accommodated in the public schools. It requires proper facilities and teachers and good communication between the diagnostic center and the school.

In a country that prides itself on providing free education for all, an unjust cost is placed on the family with a handicapped child. Public funds should provide for the education and training of children in all categories. Transportation should be considered essential to such training.

It is also essential that children with a learning problem first detected in school be referred for a diagnosis and careful assessment. Reliance on school clinics, psychological testing in schools and school counseling is not adequate. The future happiness and welfare of the child is of too great importance to deprive him of a careful study. There should be good communication between the school personnel and the diagnostic center.

Some conditions occur infrequently, notably aphasia, dyslexia and dyscalcula. For these conditions, therefore, centers, schools or classes should be provided. These classes, however, should not pose an extra cost to the family. Children with one of these defects living in a remote or isolated area, should be provided with a boarding home in a community where the facility is available. For the older age group it may be necessary to have boarding schools which combine academic education and practical training in order to prepare an individual for employment. The existing state schools, for the blind, the deaf and the cerebral palsy children, should be re-appraised to determine whether their functions need to be altered. With increased facilities to educate and train "normal" blind and deaf children in local communities, a better function for a state school would be specialized services for the multipli-handicapped. As examples of these problems the following two cases are discussed briefly:

Robert, with a severe communication problem characterized by speech which was a jargon not understandable by anyone but himself, was diagnosed at age six as aphasic. He attended public school where he received some speech therapy once a week; he was passed from one grade to another without improving his method of communication. When he was first seen at our Center he was fifteen years of age; he had a

handsome physique without stigma; his intelligence tests placed him in the normal range; he was well adjusted with his peers in the neighborhood; his family was realistic about his handicap but felt completely frustrated in getting help for the child. The staff, too, was frustrated. The boy needed to acquire enough understandable language to hold a job; he needed to learn skills in some trade where the necessity for speech was minimal. The parents had no higher ambition for him than this, but there was no class or school for the intensive training of a child with this type of problem in his home area. He was sent half way across the continent at the cost of five to six hundred dollars per month, a sum the parents could ill afford. At this school he learned cooking, a skill not requiring much speech. He acquired enough command of words to be understood. He should be self-sufficient.

Timmy, at age fourteen years with an intelligence quotient in the superior range, had been unable to acquire reading skill; he was dyslexic. He had been retained in classes; he had been tutored; he had had psychotherapy, but he could not read.Seven years of exposure to failure in an intelligent, sensitive child is exceedingly traumatic. With all the various methods of transmitting information that are available, from Braille to recordings, should a child be exposed to this type of humiliating failure for years? There is no community facility to help him.

Training for Jobs

Children with an abnormal genetic pattern, a foetal insult or an injury to the nervous system in early life are very apt to have either some degree of mental retardation or a problem in learning or an emotional overlay that distorts his self image unless he and his family have wise counseling. Many of these children cannot become proficient scholars. The academic ability can be very well determined by eleven or twelve years of age and training from then on should be oriented to useful work. Only in this way can a child's incentive and motivation be maintained. One of the most devastating experiences our children with learning problems suffer is eight to ten years of academic failure. The type of training made available to children with defects must be diversified to meet the needs of many different types of individuals. There is no way of massing these children into large groups and presenting them with a uniform program.

The schoolroom experience should be a continuum with jobs in the community or with a place in a sheltered workshop either as a separate institution or as a part of an industrial plant.

Handicapped children have assets. Richard Scammon once said, "To achieve you either must have superior physical energy or be handicapped so that you are not distracted by the frivolities of life." The person with limited physical ability

does often apply himself more diligently to his task; he has learned self-discipline and he can and does render more dedicated service than the normal individual. A community's plan, therefore, for handicapped individuals should start as soon as a child is recognized as having a defect and be continued throughout a lifetime unless the defect is wholly remedial.

The diagnostic services and the community services should set their sights on certain goals for handicapped children. As stated earlier, a growing organism is constantly undergoing change. If the normal or genetic potential of growth has met with interference, we have abnormal development with which to deal. Although we have learned considerable about the normal patterns of growth, knowledge about the abnormal or deviates is largely lacking. Furthermore, it will always be much more difficult to acquire such knowledge because injury can introduce a host of variables into the pattern, and each child practically will need individual evaluation. This is the reason that a diagnostic and assessment center is of such importance for the continuation of the study of the individual and the repeated counseling with alteration of plans as indicated. The aim, naturally, is to restore the individual as nearly as possible to functioning in a normal manner in the community; this refers to school and preparation for independent living in its broadest meaning. In reality, however, many an individual, even with the aid of the best known medical skills and the wisest counseling, must settle

for a lesser goal than this. The increased understanding in industry, the professions and other work areas, of the assets that the handicapped bring to the field, is and will make it possible for a larger number to find employment. These assets as mentioned earlier are devotion, application, faithfulness, self-discipline, lack of distraction and fragmentation of his talents.

For the more severely handicapped who even with changed attitudes will not be able to fit into the stream of work life, part-time work or full-day work in a limited way has much greater application than has been made use of to date. Bringing certain work to the individual, instead of the individual to the job, should be further explored, in all areas. In large industries it may be possible to set up areas, or an area, to which certain work is assigned or brought, and this serve as a sheltered work-shop within the plant. More and more is being learned about the abilities of handicapped individuals, and the range of work may well increase.

The individuals with even greater limitations are entitled to use those faculties they have for pleasures, hobbies or any practical application to which their endowments can be put. Let's give those who only sit and wait that limited chance to serve.

Our culture is changing, shifting and aging. Communities, small ones, or divisions of large urban ones, could be made more self-sufficient, if the part-time man- and woman-power were utilized efficiently and practically and with dignity. There is greater satisfaction in life if a day is divided into some work, some recreation or amusement, and some meditation and rest. Our patterns should not necessarily mean an eight-hour day five days a week for all people. The aged, the handicapped, and the semi-invalided may have different schedules. There should be training programs for useful services in the local area scaled to the interest and ability of the individual and the many needs.

For women, there are baby-sitting, extra hands in child care centers for both normal and handicapped children, sewing and mending in all its varieties. In a culture as mixed as ours, it would be interesting to cultivate native crafts of the various countries represented in the community.

For the men, there are gardening, repair work and crafts. If man-pools were available and skills made known, there could be a regular exchange of small part-time services.

Our educational systems need a great deal of revision in many areas to prepare the handicapped and limited people in the way of life described. Education is designed toward serving the average or great mean. Considerable emphasis has been placed on integration of the handicapped with the normal. Too

often the pro's of this method have been emphasized and the voice of the con's at the realistic level of the classroom has been muffled. The attempt to integrate all handicapped children into the normal schools without adequate preparation and continued help is like asking all the players in a symphony to play their instruments without a conductor or director to produce harmony. Children with defects cannot be turned into the turbulent stream of young lives and be expected to survive without preparation and assistance. This type of help is realistic and does not result in either over-protection or lack of faith in the child's potential.

There is a great need for experimental schools where the learning process may be studied by independent imaginative educators in close cooperation with pediatricians, neurologists, psychiatrists and psychologists.

Recreation

"On Sundays I would find my perch on the
wall near the entrance gate to the sanitarium and would watch the healthy people...
as they walked up the hill to the bus...
they owned the miracle of being able to
leave when they wanted to." -- Ibid.
Schweitzer -- Cousins

"The outside world was something of an unreality. We longed for it but it was like
pressing our noses against the windowpane
of a non-existent tomorrow." -- Ibid.

Recreation is another basic need for handicapped children. Very little thought has been given to recreation,

pleasure or hobbies of the handicapped. If any recreation has been given it has usually been limited to two weeks camping experience. When working with children, especially with the young, the joy of play, and the same impishness that is seen in normal children is so obvious. Unfortunately, as time passes, the spontaneous smile and the chuckle of amusement disappears. Similarly, the little child, before frustrations have blunted his desires, shows great eagerness and strong impulses to try any new thing. It is necessary to capitalize on a child's readiness, otherwise the optimum moment passes and one may not be able to re-awaken the same interests.

Very severely handicapped children, with extreme limitations, may still enjoy music. Music has great variety and many methods of presentation, such as records, television, radio, live, accompanied by dancing, ballet and opera. Why should not a child whose only enjoyment may be music have a chance to learn, up to his capacity, music in its many variations?

Painting is another activity that has at some time or in some way intrigued almost all of us. It is noteworthy that severely handicapped individuals have painted holding the brush by the toes, in the mouth or attached to a headpiece. Childhood is not complete unless at some time hands have been dipped in paint and splashed over a canvas.

Imagine the joy of a severely crippled child being strapped to a saddle for a canter around the green, or the blind child climbing a tree! Other activities that can be enjoyed are ball games, merry-go-rounds and swimming. Dancing can be participated in to a degree by the most severely handicapped youngsters. In some cultures the dance rhythms are limited to eye, head, finger or hand movements. There is practically no child who cannot participate to some degree,--even watching others dance may be a joy. Isn't it to most of us?

The recreation centers afford an unusual opportunity for a child to develop a hobby and for the staff to observe and note the child's talents. For those individuals who are going to be too handicapped to be self-sufficient, a hobby can be an absorbing activity, and with the kind of concentration the handicapped often apply to a task, some valuable contribution may also result. The handicapped and retarded should have this opportunity and such pleasure as they can be given. VanGogh is an example of a severely handicapped person who achieved enduring fame. Yes, some are "crackpot" geniuses! Year round recreation is essential.

The Churches

A little boy, as the plane took off into the air, said, "Are we higher up than God?"

Religion is a basic need of children. The churches have done a great deal to promote both education and health.

It is curious that the handicapped and the retarded particularly somehow seem to have been generally overlooked. Sunday is such a welcome break after six days of monotony. To dress up in your Sunday best and go to Sunday School has a nostalgia for many grown-ups. The singing, the ritual and the formality are appealing to children. The festive days, such as Christmas and Easter, have particular significance, and children's programs can add much to a child's pleasure.

Only those who have experienced the comfort of faith, the release of anxiety through prayer and meditation, know that children, especially those restricted in every way else by a crippled body, can enjoy to feel that the spirit is free even if the body is not. Upon admission to a state institution, one child's comment was, "At last I can go to church."

There are many other services the churches could provide, such as day care centers, temporary or permanent homes.

Guardianship

There are many ways beside the very simple means of Sunday School, church services and religious education in which the church can serve these children. Many children, young adults as well as adults and the aged, need guardianship. One of the inconsistencies we practice is to assess the children who are failing and note that they lack discrimination and judgment, yet at eighteen or twenty-one years we expect them

to be responsible citizens. When they fail in moments of stress, in little or big ways, they have been condemned and even executed. The church could be a big brother to some of the less severely retarded, even throughout life.

Equipment and Transportation

In addition to these five basic needs, children with handicaps often need special equipment. Many need braces, crutches and wheel chairs. The cost of these items can be a real burden to a family. Provision should be made for a central place to obtain such equipment, for the repair and exchange of it as the child grows or outgrows the need for it.

The handicapped child also needs more help than the normal with transportation. The schools in general provide transportation for their crippled children but transportation is also needed for pre-school children and for other than school purposes, such as to recreation centers and to therapy centers.

Professional Training

"In education, for example, whenever a proposal is made that looks toward increased intellectual effort on the part of the students, professors will always say that the students cannot do the work. My observations lead me to think that what this usually means is that the professors cannot or will not do the work that the suggested change requires. When in spite of the opposition of the professors, the change has been introduced, the students, in my experience, have always re-

sponded nobly." -- The Great Conversations

In the course of our previous discussions the work of many different kinds of professional people has been referred to,-- physicians in many specialties, psychologists, social workers, educators, speech therapists. How well do our schools and colleges prepare their students for work with the handicapped? Are we not still isolationists in our training programs? Physicians, particularly, are prone to remain aloof, and sometimes they are even disdainful or derrogatory, toward the work of others in related fields.

The history of Medicine goes back to medicine men, magic, superstition, barber surgery, cupping and bleeding, as well as to Aesculaepeous, Hippocrates, Galen and Hygeia. This should not be forgotten.

In Medicine, as in all branches of knowledge, adaptations occur. Like the organism itself institutions grow irregularly. Advancements are made in one area at one time or during one generation and in another the next. The final development may show little or no relationship to its origin. There is, however, a sub-strata of fluid knowledge out of which emerge at intervals new ideas. When these are usable and acceptable, an entire new discipline of knowledge may evolve. Sometimes it is necessary to eradicate entirely and rebuild as knowledge increases. In all the major disciplines that have

survived, there is an enduring core of principles. This is true in Medicine. At times rapid growth obscures the basic principles upon which the science was founded, but invariably when this happens voices are raised; there may be a time of turmoil and confusion as adjustments take place, and then equilibrium is again established.

The present state of Medicine is one of explosive acceleration in many areas at once,-- genetics, chemistry, virology, immunity, antibiotics, and so on. It behooves some in the field to keep the focus on the organism MAN as a unit and his reaction in and to his environment. It is not enough to analyze the body chemically, to mend its broken parts or even to replace missing portions. In one of the newest fields, Space Science, the intensive study of nuclear fission, mathematics and chemistry is coupled with the study of MAN in orbit. In Medicine, the study of the cellular structure and function by the research scientist and the observation of the clinician should have this same relationship.

Medical Schools in the training of scientists in the health fields must bring about this type of equilibrium. A physician entering the practice of medicine must not only be well versed in the basic sciences that are pertinent to his profession, but he must also understand his patients and their total needs as these pertain to optimum health. In the prac-

ticing field the physician has many helpers and it should be a part of medical training to help doctors to understand the roles of, and how to utilize the skills of, the paramedical and the non-medical staffs.

In other disciplines, it is equally important that a thorough knowledge of his own specialty is combined with an appreciation of the limitations of a single point of view and the role of the other disciplines. When this is not accomplished in the care of our children, the results are discordant. The physician is the logical person to direct the group. The handicapped child has recurrent health problems and all the other disciplines must go back to the basic problem and get their cues from the physician in charge.

It is increasingly apparent that it is important to have the health sciences grouped about the Medical School and to have training in the various fields related to one another and not set apart in different locales and with independent staffs or with piecemeal approaches to the child.

In the study of Homo Sapiens where do the various sciences and disciplines meet? The point of contact which appears most natural is growth and development of the young organism, before it has differentiated completely into more distinct component areas of knowledge and performance.

Curiously in Medicine embryology has been relegated to the pre-medical studies and the teaching of diagnosis and

and therapy based almost entirely on the adult, as if the moment the infant is born he is then a miniature adult who needs only to increase in size. Fortunately for Medicine, the basic sciences are emerging and are revealing staggering new insight into the structure and function of man. This newer revelation of the complexities of man will return us to the study of the beginnings of growth and development, and the factors that influence the form, structure and function of the organism. Disease will then be considered as deviation from the normal. The study of anatomy can no longer be limited to a gross and microscopic structure of organs; it will be combined with a study of function, chemistry in all its variations, hormones, enzymes and genes.

The study of the science of Homo Sapiens can be visualized as starting in the grades and continuing, with students branching off at various times in their studies, depending upon major interest and capacity. Some may have their curiosity aroused and continue the study of anatomy, or bacteriology, or chemistry; others may find the science of sociology or of psychology to be the one in which he wishes to remain.

As certain members pursue this study there will be those who wish to practice the healing art in all its many variations and with the assistance of the experts in every field. Man's behavior will always captivate the imagination and his evolution has not ceased. It will surely take major

development in Medicine to attain this goal.

Somewhere in the course of training in Medicine or other fields related to human welfare, the student must learn to resolve his own feelings and reactions toward his fellow men who are born imperfect or become defective. Man along with animals of other species tends to reject or even destroy the defective. The human side of us, that which makes us humans, can be rated by our acceptance of and rendering assistance to those who are handicapped, retarded or mal-formed.

Prevention

Tightening Up Our Defenses

"The gardener said that a tree of this kind took two hundred years to reach maturity. 'In that case,' said the marshal, 'there is no time to lose. Plant it today'." -- The Great Conversations

Medicine has come a long way in the battle against disease. This has been accomplished by many and varied means, public health measures, immunizations, surgery, anaesthesia, antibiotics and also by education and improved economies. The present accelerated speed of discovery promises continued victories against the still unconquered maladies of man. Are we, in our quest for the dramatic, omitting some of the simple and obvious preventive measures? There is nothing as humbling to

a physician as a disease induced by himself. Many such tragedies have and are occurring.

Drugs

Drug-induced pathology should come first on the list of iatrogenic diseases. The list of these conditions was long, before Thalidomide produced thousands of malformed babies. There was blindness from excess oxygen, deafness from hydrostreptomycin, deaths from chloromycetin; there have been others and there may be many, many undiscovered or unrecognized sequelae to the indiscriminate use of drugs. To those of us in the pediatric field it is especially disconcerting that so little thought has been given to the peculiarity of the young or growing organism to drugs. This defect in our thinking stems in part at least from our failure to study adequately embryology, and foetal and child growth. It is basic to prevention in this area of therapeutics that the young cease to be considered as miniature adults. Drug prescribing cannot be done on a mathematically reduced basis.

Pharmacists and pharmaceutical firms should have the same code of ethics as physicians. As physicians, have we not sold our birthright for a mess of pottage when we depend on advertising of drug firms to support our Journals, entertain us at medical meetings, pay for graduate education

and dole out money for research? Is it right that we encourage the type of competitive enterprise that fosters taking risks with human health? Is it correct to place this additional cost burden on our families?

Para-natal Hazards

One of the earliest emphases in both public health and private medicine was on maternal care. A great deal of progress has been made as mortality and morbidity figures show. Great emphasis has been placed on prevention of prematurity. Prematurity is a hazard but there are other factors that introduce hazards to both the premature and the full-term infant. A recent look at over six hundred twin infants and their birth records showed that only one death could be attributed to trauma, but over one hundred of the children had need for oxygen. Drugs and anaesthesia contribute to newborn distress. Newborn distress has a high correlation with later problems of children, especially in the learning areas and the now termed neurologically handicapped.

There are other factors contributing to crises of birth,-- particularly important are blood incompatabilities. Careful observation and prompt therapy have saved many children from permanent sequelae, but vigilance must be maintained.

Surgical Risks

Remarkable advances have been made in both surgical techniques and in anaesthesia. It is difficult to say which of these has contributed the most to improve recovery from surgical procedures. It must be noted that neither the surgeons nor the anaesthetists have had adequate training in pediatrics and the unique risk posed by a growing organism subjected to a stress well tolerated by an adult. The risks of surgery are many,-- drugs, hypoxia, prolonged anaesthesia, shock, cardiac arrest, dehydration, over-hydration, emotional trauma. Anaesthetists and all surgeons, regardless of the subspecialty that is practiced, if they deal with children, should have training in growth and development and the risks peculiar to the young.

Infection

Although immunization and antibiotics have greatly reduced and almost eliminated many infections, not all morbidity has been prevented, and in some previously fatal diseases the incidence of handicap has increased. Direct infection of the nervous system obviously poses the greatest hazard. The danger is increased the younger the child, the greater the duration of the disease before treatment is instituted, and the type and severity of the infection. Very few children in the first one to two years of life escape without sequelae from such diseases as encephalitis and meningitis. Many older children

show varying degrees of temporary or permanent impairments. Prompt diagnosis and adequate treatment constitute the best preventive measures when immunization is not possible. The children who have had a central nervous system disease should be carefully assessed and parents and schools counseled until the child's functions are as nearly as possible restored to normal. Infections, as is now well documented, at least in German measles, may seriously handicap the foetus. Immunization for a disease that has been considered mild must therefore be considered.

Infections other than those of the central nervous system may also be a hazard. The dehydration and toxicity of diarrheas often cause central nervous system damage. The toxins of other organisms, particularly pneumococcus and staphylococcus, may also impair the brain. It must not be forgotten that the drugs administered for infection may also be harmful. Deafness from hydro-streptomycin is an illustration. Again, in the diseases for which we have no immunization, prompt diagnosis and adequate safe treatment is the best recourse.

Poisoning

Lead, the classic poisoner, is still a hazard even though many sources of the past have been eliminated. The controversial "Silent Spring" has alerted us to many of the

dangers latent in the food we eat whether frozen or canned, the detergents with which we wash our dishes, the sprays in and out of the house and the poisons falling or windblown uncontrolled from the atmosphere. The home adds to the above hazards those of candied aspirins, parents' tranquilizers and grandma's sleeping pills, to mention but a few of the household dangers.

Bodily Injury

The prevention of both poisoning and accidents has been vigorously supported by the Academy of Pediatrics, the National Safety Council and by other national organizations. In the younger age group poisoning is the more common accident. Bodily injury occurs more frequently in the older child. Skill fracture, with or without subdural or epidural hematomas and without accompanying gross hemorrhage, still has a high incidence of sequelae. Again, the younger the child the greater the hazard. The children who have had head injury should be followed with electroencephalograms, psychological testing and educational evaluation and counseling until the possibility of any even subtle sequelae has been determined.

Inborn Errors of Metabolism

As more diseases due to error of metabolism are discovered it becomes mandatory that these conditions be de-

tected early and when therapy is available the child be given such benefit as therapy provides at the earliest possible moment. At present the known diseases that benefit from early recognition and treatment are cretinism, phenylketonuria and galactosemia. In our experience these diseases like other birth defects are very often associated with other deficits and treatment may greatly improve the condition but the child may still not attain normal development in all respects. This knowledge is important. When it is not known, defects may be attributed to either inadequate or late treatment, which may not be the case.

Genetics and Youth Counseling

The trend to introduce science early in the educational program is increasing the sophistication of our youth. The teen-ager may be concerned about the potential of a hereditary disease in the family. This may be one of the most hopeful means of partially controlling the severe metabolic and chromosomal diseases. The general emphasis on population explosion may make voluntary control more desirable. To those who have no children or should not bear them, emphasis on the many ways in which our children need help, such as by adoption, foster home care, in education or recreation, should in many instances be an adequate substitute for the risk of producing a defective individual.

Youth counseling should aid in other ways. There is an optimum time for child bearing. The young should know this. If parental discipline breaks down, the self-discipline of youth should be encouraged. Early counseling should diminish the use of alcohol, tobacco and drugs, and other habits that may be injurious to their health and that of the offspring. Faith in youth is important.

Although future research may reveal new methods of preventing defects, the past experience indicates that new discoveries bring new problems. A great deal can be accomplished now with the knowledge we have if we all will tighten up our defenses.

Redevelopment

Is there need for any great change in our care of children? When a housing division has become antiquated, the plumbing out-moded, or termites have undermined the structure, it is customary to remodel or tear down the old and rebuild the area. Institutions and agencies, like houses, get out-moded, and when they are, redevelopment is as important in the latter as in the former. What are some logical changes that will improve the health programs for our children?

Indigency

In the first place, it should be self-evident that there should be no indigent children. There may be indigent parents, but our children should not suffer discrimination in health care because of the family's inability to pay for it or indifference regarding it. If children's health needs are provided from public funds, the federal, state or local agency should contract with the existing pediatric departments for their services. Children should have the health care that they need irrespective of the families' financial status.

Hospitalization

The aging population, with increased emphasis on geriatrics, has changed hospitalization to such a degree that there should now be more hospitals exclusively for adults, and the children provided for according to their peculiar needs in separate hospitals or wings of only a few general hospitals. The emphasis by Accreditation Boards, Hospital Boards, Administrators, Staffs and Medical Schools on four clinical departments, Medicine, Surgery, Obstetrics and Pediatrics, has become a way of thinking that needs to be changed.

In contrast to adults, and particularly the aged, children are hospitalized infrequently and for very short periods of time. Even the children with chronic diseases

are cared for in homes and in hospital ambulatory services. As long as all hospitals, or nearly all, have a Pediatric Department set up on the same basis as the other clinical services, pediatrics suffers. Occupancy is low. The department, by the standards of the other departments, is on the debit side. Furthermore, it becomes extremely difficult to establish an adequate training program for accreditation. This means the children get the short deal. In other situations, such as rehabilitation programs, specialty clinics in hematology, endocrinology, neurology, hearing centers, if designed for adults and children, the children again get the short deal. Orientation is toward the majority. The children's problems in any of these situations vary markedly from those of adults. If we are going to have proper services for our children this type of fragmentation must be eliminated. Our children must be grouped together where professional personnel trained in pediatrics, and in development of children, may concentrate on programming to meet childhood's needs. This will mean a re-orientation of medical thinking in Medical Schools, Hospital Centers, Accreditation Boards and Medical Societies, but it must come about if we hope to give proper care to the children and well rounded training to professional staffs.

A Child Development Facility

A division within the Pediatric Department for the total assessment of the child, medically, educationally, emotionally and socially, either in a Child Development Center or a similar facility, should be as essential as is the clinical laboratory, with a pathologist in charge of a para-medical staff. Such a diagnostic facility should be open to all physicians for referral of patients regardless of the patient's financial status. It should be adequately staffed, properly financed and administered.

Risk Registry

In order to detect minor deviations early and also to increase the skill in diagnoses, obstetrical departments, newborn nurseries and pediatric services both medical and surgical, should keep a risk registry. Obstetricians have a great deal of information about maternal health that may jeopardize the foetus; diabetes, hydramnios, German measles, age, incompatability, previous lost pregnancies, bleeding, threatened abortion, familial hereditary diseases, and so on. Some of these pose a greater risk to the foetus than others; the hazards could be given ratings. Similarly in the newborn nursery the risks are known. Babies may be born prematurely, they may be small at birth even at term, they may be born

with congenital anomalies; regardless of size or age they may be exposed to distress at birth, to blood incompatability, to hemorrhage, to trauma, to infection or a combination of any two or more of these stresses. These risks also should be given ratings. Infants and children undergoing surgery may have periods of apnea, they may have cardiac arrest, excessive blood loss or dehydration. Skull fractures and concussions are risks. Meningitis, encephalitis, dysentary, severe toxemia, and even the drugs used for therapy may have ill effects on the central nervous system. These diseases in infancy and early childhood particularly are a risk.

Community Responsibility

Practicing pediatricians and physicians serving children must assume leadership in community planning for children with handicaps. All the health agencies, the school programs for education of the handicapped, the homes for abandoned children, nursing homes for the handicapped, and adoption programs all need medical participation. The final authority in health is the doctor. In planning for all the still un-met needs for the handicapped, a physician's counseling is essential.

Research and Practice

Instead of attempting to combine the practice of medicime, in other words, service with research, the clinician and the research scientist should be colleagues. The placer

gold in research has been fairly well exhausted; basic research now requires special knowledge, instruments, techniques and time. It is unrealistic to expect the clinician to do both research and practice clinical medicine. It is equally unrealistic to expect the laboratory man to have the skill and art of the clinician. Clinical observations, however, are of extreme importance. If the practicing physician had a research scientist as a colleague to whom he could bring his observations and his clinical material there would be a greater chance to find break-throughs in our ignorance.

Education and Service

In teaching, similarly, undergraduate students need the undivided attention of a teacher. The patient needs the undivided attention of his physician. This ideal could be achieved if the clinician and the teacher were colleagues. The clinician could keep the instructor supplied with the number and kind of patients he and the students needed for the lesson while he continued the service part of the clinic. This method has been used very successfully in the Child Development Center with other disciplines, namely nursing, public health, educators, physiotherapists and occupational therapists.

Epilogue

Children are important. They are our greatest asset. They all should have an opportunity to develop to their greatest potential. This nation has and is doing many things to help children attain this goal. In the last several years concern for the handicapped has come to the fore. The money and the know-how to improve the lot of the child born imperfect or injured later is available. It will take major re-development in the health and social sciences to accomplish the goal. Let's start now!

In other disciplines as in Medicine small beginnings have gradually expanded and a great deal is known regarding ways and means of helping the child less than perfect.

Psychology

Kanner, Leo. Child Psychiatry. George Banta Co. 1957.

Jersild, Arthur T. Child Psychology. Prentice-Hall, N.Y. 1954.

Psychoanalytic Study of the Child. 1964.

Satir, Virginia M. Conjoint Family Therapy. Science and Behavior Books. 1964.

Witmer, Helen L. and Kotinsky, Ruth. Personality in the Making. Science and Behavior book. 1964.

Communication

Freud, Sigmund. On Aphasia. International Univ. Press. N.Y. First pub. in 1891.

Cass, Marion T. Speech Habilitation in Cerebral Palsy. Columbia. 1951

Jordan, Raymond E. and Eagles, Eldon L. Hearing Sensitivity and Related Factors in Children. Laryngoscope. St; Louis, Mo. 1963.

Disorders of Language. Ciba Foundation. 41 Portland Place. London 1964.

Money, John. Reading Disability. Progress and Research Needs in Dyslexia. Thomas 1957

Visual Handicaps

Hathaway, Winifred. Education and Health of the Partially Seeing Child. Colombia Univ. Press 1954.

Lowenfeld, Berthold. Our Blind Children. Charles C. Thomas. III 1956.

Spencer, Marietta B. Blind Children. Lund Press Inc. 1960.

Education and the Handicapped.

Baker, Harry J. Introduction to Exceptional Children. MacMillan. 1954.

Ingram, Christine P. Education of Slow Learning Children. Ronald Press. 1953.

Gallagher, James J. The Tutoring of Brain Injured mentally Retarded Children. Charles B. Thomas 1960.

Cruickshank, William M. et al A Teaching Method for Brain Injured and Hyperactive Children. Syracuse 1961

Clough, M.F. Teaching the Slow Learner. Philosophical Library. 1961.

In the Fields of Physiotherapy, Occupational Therapy and Recreation there also are books appearing.

Rachel Carson Silent Spring Houghton Meffin Co. Boston 1962

Bobath K. and Bobath B. An Assessment of the Motor Handicap of Children with Cerebral Palsy and of their Response to Treatment. Occupational Therapy Journal. London. pp 1-16. May 1958.

Willard, H.S. and Spackman. Occupational Therapy. Lippincott, Philadelphia. 1963.

Pomeroy, Janet. Recreation for the Physically Handicapped. MacMillan 1964.

Two books pertinent and interesting in other fields are:

The New Knowledge of Dog Behavior. by Clarence Pfaffenberger. Howell Book House, Inc. 1963.

There are also books that are of special comfort to the patient, parent or family:

Carlson, Earl R. Born That Way. John Day 1941.

Buck, Pearl The Child That Never Grew. John Day and Co. 1950.

Brown, Christy. My Left Foot. Secker and Warburg. 1954.

Kirk, Samuel A. Karnes, Merle B., Kirk, Winifred D. You and Your Retarded Child. MacMillan 1955.

Lewis, Richard S. Strauss, Alfred A., Lehtinen, Laura E. The Other Child. Grune and Stratton. N.Y. 1960

Education and the Handicapped.

Baker, Harry J. Introduction to Exceptional Children. MacMillan. 1954.

Ingram, Christine P. Education of Slow Learning Children. Ronald Press. 1953.

Gallagher, James J. The Tutoring of Brain Injured Mentally Retarded Children. Charles B. Thomas 1960.

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Pomeroy, Janet. Recreation for the Physically Handicapped. MacMillan. 1964.

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Carmen, Rachel Silent Spring - Houghton Miffin Co. Boston 1962.

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Buck, Pearl The Child That Never Grew. John Day and Co. 1950.

Brown, Christy. My Left Foot. Secker and Warburg. 1954.

Kirk, Samuel A. Karnes, Merle B., Kirk, Winifred D. You and Your Retarded Child. MacMillan 1955.

Lewis, Richard S. Strauss, Alfred A., Lehtinen, Laura E. The Other Child. Grune and Stratton, N.Y. 1960.

Smith, Bert Kruger No Language But A Cry. Beacon Press 1964.

A TREATISE ON CHILDREN WITH IMPERFECTIONS

"Know you what it is to be a child?...
It is to believe in love, to believe in
loveliness, to believe in belief; it is
to be so little that the elves can reach
to whisper in your ear; it is to turn
pumpkins into coaches and mice into
horses, lowness into loftiness, and nothing
into everything, for each child has its
fairy godmother in its soul." -- Shelley

What is it like to be born with a handicap? How and when does the child become aware of his defect? How are his interactions with others affected by his imperfections? What image of himself does he develop?

Improved control of infectious diseases by public health measures, immunization and antibiotics, has freed the pediatrician to devote time and thought to the growth and development of the young and the deviations from the norm. The advancement in the basic sciences of genetics and chemistry has enhanced his understanding of abnormal patterns of development. The continued study of the structure, function and inter-reactions of the whole organism on the one hand, and the ultra-microscopic nature of the substance of which that organism is constituted on the other, has the potential to initiate a new and enlightening era in pediatrics.

Intimate work with both children well-formed and those with flaws and defects in design has afforded opportunities to note similarities and differences.

Dixie Elvord
1966

A TREATISE ON CHILDREN WITH IMPERFECTIONS

Introduction

In the Beginning - - - - -

In 1952 a telethon sponsored by the parents of children with Cerebral Palsy netted a surprisingly large sum of money. As a result, a meeting was called in San Francisco to discuss the development of programs for cerebral palsy victims. As chief of the Department of Pediatrics of Children's Hospital, I was invited to the meeting. In preparation for the meeting I discussed with the director of physiotherapy the local unmet needs in the field of Cerebral Palsy. Her immediate response was, "For the children under three years". In 1945 a law was passed in California making funds available for help to children with cerebral palsy from birth to 21 years. The funds were allocated through the Department of Education to develop total programs within school systems to care for the children. In San Francisco, a school for children with handicaps antedated the new law by many years. The major difference between the proposals of the new law and the organization of services in the "Sunshine" School in San Francisco was that the latter provided for therapy through the Department of Health instead of through the Educational Division. Children were eligible

for admission to the school at three years of age. This left the pre-nursery school child without therapy. In the programs developed later in the state, physiotherapy and occupational therapy were provided in the school clinic regardless of the age of the child and whether or not he was enrolled in the school.

At the above mentioned meeting in San Francisco, I was alerted prior to the discussion that an effort would be made to have the program for infants and young children at Children's Hospital. The city at that time had two Medical Schools, and a neutral as well as non-sectarian place such as Children's Hospital seemed desirable.

The news of this choice was in the papers before there was any chance to consult with the Hospital Board, Administration or Staff. As sometimes happens, unfortunately, this publicity made it somewhat difficult for the program to get off to a smooth start.

The Department of Pediatrics was well prepared to launch a pre-nursery school service for handicapped children. For several years a weekly seminar on childhood ecology (1) had made the staff not only knowledgable about normal growth and development but also acquainted it with the facilities for children in the community. An additional advantage was my experience with rehabilitation services in the Veterans'

Administration Hospitals, to which I had been Areal Consultant since World War II. It was not difficult to adapt the knowledge and experience gained in the Veterans' Administration to the young handicapped child. As a special preparation, Dr. Rusk's program at Columbia University was visited, and a day was also spent at the John Tracy Clinic in Los Angeles. It was Mrs. Tracy who gave me the courage to start "now". Her words were to the effect,-- Get a toe in the door and start; you will learn best by doing. The years of experience have shown the wisdom of that statement.

The school opened August 1, 1952. Space was made available in the main room of the Physiotherapy Department by shifting the patients usually seen there to other times and other rooms for two afternoons a week. The director of physiotherapy and the director of occupational therapy assumed responsibility for the work with the patients. The executive secretary of United Cerebral Palsy made her headquarters in the Hospital. Her skill and devotion to the program and to the Hospital for the short time she was secretary added immeasurably to the beginnings. It was a united, close-knit staff that launched the program.

Organizations, national in scope, are prone to have somewhat rigid regulations. Before opening, therefore, it was requested that in a disease as ill-defined as Cerebral Palsy, a rigid diagnosis in early infancy not be demanded;

that the upper limit of age not be rigidly set at three years but transfer to a public school be left to the discretion of the staffs of the two involved programs, and at least until neighboring counties had time to develop their own programs county lines not be stringently enforced.

The demands for the type of service offered were surprisingly great from the start. The program from the beginning was designed to be a habilitation service for all children in need of such help. It was not set up as a medical facility only, nor was it set up within the framework of the traditional Out-patient Clinic subject to eligibility requirements. It was open to all doctors and medical facilities for referral of patients in need of the type of program offered. (2)

Not long after the launching of the nursery school, the Crippled Children's Service of the State authorized a neurological diagnostic clinic to the Center. (3) In order to accommodate children not strictly cerebral palsy, and not eligible under Crippled Children's Services, the Little Jim Club, a hospital auxiliary, was asked for and it contributed a supplementary fund to the program. Since children with many types of deviations from the normal were admitted, the name was changed to the Child Development Center. In 1961 the first grant was received from the National Founda-

tion -- March of Dimes -- to open a Birth Defect Center as a part of the services. This move was particularly appropriate because Children's Hospital had been a center for poliomyelitis and the staff had worked intimately with the Foundation since its origin. The rapid increase in volume of work since 1961 attests to the need for services of the type given in the Center for children with imperfections and to their parents.

The basic organization of the Center was patterned after the rehabilitation services for adults already in existence, such as the Veterans' Hospitals, the John Tracy Clinic and Howard Rusk's Center at Columbia Presbyterian in New York. The Clinic for Mental Retardation at Flowers Hospital in New York and the out-patient services at Cornell Medical Center were visited also, and the personnel in these centers supplied helpful information. The probable reason that the organization has changed so slightly from the original plan is the a priori work done.

The Center is a multi-purpose center providing medical diagnosis, total evaluation of the child, diversified therapy to meet the medical needs and also to meet the needs of a variety of sensory handicaps, such as speech, reading and other learning difficulties, family counseling, follow through therapy, repeated re-evaluations and follow-up studies.

The medical staff has a pediatrician in charge and as many pediatric assistants as the volume of work dictates. The pediatricians have a complete panel of medical consultants available, namely, neurologist, neuro-surgeon, orthopedist, ophthalmologist, otologist, pediatric surgeon, plastic surgeon, psychiatrist, dentist. A physiatrist supervises the work of the physio-therapist and the occupational therapist. The laboratories of the hospital are equipped to carry out all necessary procedures.

The non-medical staff members are nursery school educators who have general charge of the nursery school and individual educational evaluations, the social workers who perform a superb service with the parents and the personnel in the community agencies, the psychologists who are specially trained in child development and the tests sppropriate for children with various sensory deficits and physical handicaps. The psychologists are also available for counseling. The other members of the staff are the physio-therapist, occupational therapist, speech audiologist, remedial reading and the secretaries.

There is no rigidity about the procedure of study but in general it follows a pattern as here described. A patient is referred by a physician or Medical Clinic. The patient is seen first by a pediatrician and the standard

pediatric work up is performed. This part of the study includes such laboratory examinations as are indicated by the medical findings, X-rays, EEG, blood counts, urinalyses, chemistries, metabolic tests and chromosome studies. When the findings call for medical consultants a series of these appointments are arranged. Necessary medical treatments and surgical procedures are carried out.

Either following or interspersed with medical examinations are the studies by the other professionals, such as psychological examinations, speech and hearing evaluations, educational and social studies. Various therapies may also be carried on even while other diagnostic studies are being pursued.

There is plenty of opportunity for inter-communication between staff members and in a high percentage of cases a large conference is held when the studies are completed to which the referring physician and community personnel involved in the problem, educators, social workers, visiting nurses and sometimes government and legal representatives are invited. The study and conference result in a long term carefully planned program of therapy, counseling and follow through with frequent re-evaluations in part or in total as indicated.

It should be recognized that with the many different types of patients seen, the study and programming varies

greatly with each child. Some children who come in have been carefully worked up and are admitted directly to therapy; others are referred in from a distance for a complete diagnostic study, and when completed therapy must be sought in the local community.

The nursery school is conducted five mornings a week from 9 to 11:30. Each session is limited to ten children. Some children come once a week, some two or three times, and some five mornings. The time spent in the nursery school is decided by the therapy team, the nursery school teacher being in charge. A fragile, young child of two years may tolerate only an hour in the group. The child may be placed there while the mother talks to the social worker. The nursery school serves both for therapy and for observation. (4) The therapy aims to prepare the child for the next learning experience. Those with major orthopedic handicaps are eligible for public school special education at three years of age. The Department of Education also has a school for the deaf, one for the severely retarded children and special classes for other types of handicaps.

During the afternoons, there are two days of sessions for speech stimulation of young children, two afternoons for educational evaluation and work with pre-nursery school children, and one afternoon for a follow-up joint medical and non-medical clinic.

The psychologist, speech audiologist, social worker and physician carry on work by appointment simultaneously with the above activities.

Although the structure of the program in the Center has been modified only slightly, the philosophy and concept of the staff have changed considerably with the years of experience. The staff has been stable; the few changes that have been made have not been disruptive as new members have been selected with care and interviewed by all the members of the staff. The focus has always been on the child and his family; this leaves little time or thought to inter-personal staff discords. There is no hesitancy in answering a mother's question by saying, "The social worker can be of greater help to you in answering that question", or, "Let's ask the doctor to answer your question".

In the next division an attempt is made to portray the problems of children with handicaps, of their parents, of siblings, of neighborhoods and the community as viewed after a dozen years of experience.

Our Children

"Children's griefs are little, certainly;
but so is the child, so is its endurance,
so is its field of vision, while its nervous
impressionability is keener than ours."
-- Shelley

It may be startling but it is not improper to think in terms of human design. Anthropologists have studied the physical characteristics and types of mankind. (5) Animal breeders and fanciers are very aware of perfection both of form and of function. The mental image of good design in children has evolved subtly from probing into the possible etiologies of the abnormally developed child. This image of good design becomes the background for analyzing those born with abnormalities or ~~acquiring~~ born injury acquired during the growing phase.

Unfortunately, the constant addition of new knowledge in the sciences has crowded embryology into the college or pre-medical courses. Furthermore, the basic study of medicine is done on the adult with the consequence that the child, by most medical specialists and even by some pediatricians, is considered a miniature adult and treated as such. This is reminiscent of the early scientists who first looked at the ovum under the microscope and anticipated viewing a miniature human figure. (6) Development is by design. The blueprint is formulated very early indeed, and the pattern is

diligently followed. It may be faulty, however, and it may be altered.

Those individuals with abnormal chromosomes we now know have a special pattern that in many instances is readily recognizable. These syndromes were described long before chromosomes were counted. Into this category fall the syndromes which have been labeled in textbooks as Klinefelter's, Turner's and Downs', named after the physicians who first described the entities. Although such names will persist for a long period of time as rather weird memorials to these men, the modern numerically oriented age undoubtedly will prefer a name such as Trisomy 21. There are other syndromes due to faulty chemistries or enzymes and the list of these is growing rapidly. In this latter category are the phenylketonurias, aminoacidurias and galactosemias. It is fairly easy with the new laboratory methods to screen the individuals for the larger classifications. Most of the children in the above categories have telltale stigma when looked for. There are primitive hand markings, crooked fingers, overlapping toes, webbed digits, oddly shaped or low set ears, too widely or too narrowly set eyes, peculiar hairlines, abnormal teeth, high narrow palates, Kayser-Fleischer rings and innumerable other little giveaway signs, -- signs which bring to mind phrenology and palmistry.

The child who has suffered insult in foetal life may present a variety of symptoms depending on the type, duration

and timing of the injury as well as on the original design of the foetus. The end result may be severe malformations as the picture seen after rubella in early pregnancy. The newborn then may be blind, deaf, retarded and have gross muscular disabilities. On the other hand, the effect may be as subtle as dyslexia, an inability to learn to read, an abnormality which may go unrecognized until school age.

The effects of foetal injuries at term again will vary with the severity, duration of the insult and with the stamina of the foetus. A well designed infant with a good pregnancy record may withstand hypoxia or trauma at birth remarkably well. A poorly designed, or stunted, foetus, may succumb to the same type of stress. An infant born normal who is injured after birth, for instance a child who suffers a skull fracture early in life, even if severely retarded as a result of the injury, can be recognized as being different from the child with multiple stigma. Similarly, a child with blood incompatability may proceed with normal development through the foetal period and then sustain injury from hyperbilirubinemia. Such children present a picture that is different from that of the child of poor original design.

Children are also seen with post-encephalitic and post-meningitic syndromes. No child is necessarily immune to these infectious diseases. The correct interpretation of the child's abnormalities usually can be arrived at by the history combined with the physical examination and total evaluation

of the child.

When a foetus suffers injury from any source, it must be assumed that to some degree the entire organism is affected. This does not preclude major pathology in some particular organ. This we know depends upon the timing of the insult in relation to a particularly rapid growth phase. At times, more than one anomaly will help to date the time of the insult.

In a study of children with defects, (7) it was found that 70 percent were on or below the 3 percentile in height and weight. This type of total stunting of an organism has been demonstrated in chicks subjected to a teratogenic agent. The chicks not only have anomalies but they are small, fragile, and have a shortened life span. This stunting is basic and cannot be attributed, as it sometimes has been, solely to poor appetites, difficulty in eating, and neglect.

The effect of the injury on the whole organism is also apparent in the multiplicity of abnormalities. The commonly encountered associated defects are visual, hearing, speech, dyslexia, perceptual problems and deficiencies in discrimination and judgment. Even with normal intelligence the children have difficulty in acquiring the proficiencies of their well-designed counterparts.

In the more subtle abnormalities, often the result of slight hypoxia before or at birth, the child gives the impression that the "finishing touches" have been omitted. He often has mixed dominance or is left-handed. His motor coordination is poor, his attention span is short. He may tend to perseverate, and he frequently has difficulties with communication, either oral or written. (8)

Even when growth has been interfered with seriously, the developmental pattern tends to follow the same chronological order as the normal. It is therefore essential that therapists and diagnosticians know the normal pattern of physical, mental and emotional growth.

When working daily with children who are blind, deaf, lame, grotesque or retarded, it is the child behind the handicap that emerges, and the likeness of this child to all other children places the imperfections in a new perspective. As has been rightly said, we are all a little queer. When this is recognized it is easier to view with equanimity those with greater deviations or imperfections and relate or interact to the personality of the individual regardless of the form in which he dwells.

The child trapped in the most uncomfortable body enjoys the experience of new sights, new sounds, new touch. These experiences can be brought to him. Like normal children, the handicapped child likes to splash in water, and to dab with

finger paint. The child who has been unable to crawl or walk until two or three years of age goes through his exploratory phase late; he may go through it faster and with more sophistication, but he has his fling at it. Even the most handicapped child, at the appropriate developmental stage, will show curiosity and explore his ideas of sex,-- why are there girls and boys,-- and in his own way reach some conclusion regarding the future role of girls and boys as mamas and papas. A severely retarded girl, at eleven years, began to ask the questions regarding the roles of boys and girls and mamas and papas that are ordinarily the concern and curiosity of children between three and five years.

Like normal children, the handicapped children often have a fine sense of humor, they will be impish, and they can have tremendous motivation, persistence and curiosity.

They form deep and lasting attachments to each other. Michael, a boy of eight years, a severe rigid athetoid from kernicterus, after transfer to a State Hospital developed an affection for a hydrocephalic boy in the adjacent bed. Both were confined to their beds, neither could speak. Muscle control was so poor that hand communication was impossible. They showed deep concern when separated, and were happy when brought together again. The personnel in charge recognized and honored the attachment and the boys were content. David,

age four years, with a severe quadriplegia and without speech, formed a deep and protective concern for a severely handicapped little girl in the nursery school. Susan, among other things, had difficulty in balancing her head, and in spite of his own severe communication problem he would call the attendant's attention to her when she got into an uncomfortable position. He would not go outdoors to play unless she was brought out also, and he did not wish to leave the nursery until the girl's mother called for her.

Illegitimate abandoned twins were picked up by the Protective Society at the age of two years. Penny, as a result of a subdural hematoma, is severely retarded. Patsy has an I.Q. of between sixty and seventy. Neither girl walked until over two and one half years of age. Early they were in a foster home with three other handicapped girls. They attended our nursery school until they were transferred to the School for the Handicapped. The foster mother was a sensitive, loving person and the children were happy. The foster mother died suddenly and unexpectedly. The children in her home were scattered and Penny was placed in a state institution. The foster children who remained in homes in the city continued to be followed at the Child Development Center. After five or six years, when the girls had reached the age of eleven years, Patsy who was still in the community, ~~when visiting the Center asked~~ me, "Who was born first, me or my sister?" This question was readily answered. Her next

question was, "Will I ever see my sister again? I miss her so much." Arrangements were made for her to see movies of herself and her sister taken when they were both in the Nursery School. Patsy requested that these be re-run five or six times. Later ~~it was arranged for the~~ Bernard foster mother to take her to call on Penny in the State Hospital. On her next visit to the Center she said, "Some day I want to take care of Penny myself." Patsy is in an ungraded class in school. At the foster home she is very much liked; she is gentle, kind and helpful. She is somewhat lacking in judgment and discrimination. Her academic achievement is below normal.

These children, like their normal counterparts, are sensitive to the adults about them. Good and bad days coincide with the mood of the mother. When she is tired and discouraged the child does not perform well. Acceptance by a staff of workers tides the children over such periods. When leaving the surgical ward after visiting a child in casts, the physician heard her say to the other children, "She loves me."

Many parents have said that the Nursery School program has helped them more than the children. The longer one works intimately with these little tots, the more certain one becomes that the experience is also very helpful to the children. To them is brought the experience that normal children seek and discover on their own. They learn the feel of running water,

they dip their hands in paint and smear it; they wander, in wheel chairs, on crutches or on tricycles, over to the laundry, to the engine rooms and up to the cafeteria line. They are taken to the zoo; they ride on the merry-go-round. They listen to music; they celebrate holidays. They are accepted by many adults, their staff and other children's parents. Even those who it is later found necessary to place in state institutions are more relaxed and happier. Their early experience has been a help to them. They should not be denied this bit of happy memory of babyhood. Many severely handicapped children have long memories.

The less severely handicapped child, the one that parents and teachers do not want to set apart but want to integrate into the normal group, sometimes suffers more emotionally than does the one with greater defects. Adults forget how sad and humiliating it can be to a five-year-old not to be able to hop; or a six-year-old in the first grade, to be baffled by words and numbers when the rest find learning to read an enchanting experience; or to have a classmate query, "What is wrong with your arm? Why can't you catch a ball?" Children who have been happy, smiling, roguish nursery tots come back sober with hurt, grave little faces.

When does a child become aware that he is handicapped or different? This varies with the child, his intelligence, and

sometimes with the types of exposure to information. Michelle, at four and a half years, while watching a Cerebral Palsy program on television, turned to her mother and said, "I am handicapped." Michael, not more than four years of age, was able to make many sounds but had no real speech; suddenly, one day he appeared to realize that what he was attempting to say was not understandable. Robert, at seven years of age, came home from school one day and asked his mother, "Have I had polio? Is that why I can't use my arm?" We forget that children are born with potential but not with knowledge. Information is acquired. The person who has been whole, who has had speech or who has had vision and loses it, is very different because of the experience he has had, from the child born with an amputated arm, or born deaf or blind. Also, as in all other areas of learning, total comprehension is slowly acquired. Parents of normal children use a Spock (9), a Holt (10), or a Gessel (11) reference book. We have no similar studies on children with defects. It is often said of normal children, "They are so cruel to a child who is different." Children are not cruel. They lack experience; they are often thoughtless, but more often they are embarrassed by a difficult situation, and to deal with it react with laughter, teasing or ridicule. It is not uncommon to see adults react similarly.

Children are direct and fair. An explanation by an understanding adult quickly reveals the child's eagerness to

be helpful and kind. Parents, teachers and neighbors need to appreciate this. Robert's mother replied to his question about polio by saying, "No, you did not have polio, but you had a disease very much like it and it left your arm weak." Then she added, "It won't get any worse, and you know how many things you can already do with it." The nursery school teacher recognized Michael's dilema when he discovered he was not using speech, and reassured him by saying, "Michael, your speech is not yet clear, but you can help us by pointing to what you want." It must always be assumed that a child takes in much more than he can give out.

How do you answer the child who says, "Mother, why did you born me this way?" The child who is born with or has suffered injury to the brain will almost always deviate from the normal in some learning process. Some of these variations are extremely difficult to understand, and hence to teach to others. Color-blindness, for instance, is fairly easily understood because black and white and color are everyday experiences. It is not uncommon to know that a person who has suffered a stroke may have difficulty with speech or with memory for names of familiar objects and these have to be re-learned. Experiences like these help us to understand the child with aphasia or the child with word blindness. An American Indian father of a dyslectic boy said, "I can't read either; all those little crooks look alike to me." To a Westerner, Chinese characters all tend to look alike, too.

There are children with even more difficult visual perceptual problems. A perceptive teacher noted that Pamela recognized her teacher and classmates in the schoolroom, but when she encountered them in new or strange places she might ask to be introduced to them. Experiences with individuals who have these problems are disconcerting and to the novice can be very disturbing. It is not surprising that these misunderstood children either get angry and act out, or else get discouraged and withdraw. Even more simple problems in learning will greatly disturb a child and unless he receives help early he will show emotional scars from the experience. Truancy from school is one of the first overt acts. This again may be followed either by acting out, which may lead the child into delinquency or crime, or by withdrawing and becoming a neurotic or even a psychotic individual.

Fortunately, at ten or twelve years of age, children begin some self analysis as well as some analysis of parents and other adults. Frequently at this age, the handicapped child will gain control of his impulses and show marked improvement. This is particularly true of the hyperkinetic child. A child who has been considered rather incapable may suddenly begin to organize his behavior and function better than anticipated. Other children may have greater difficulty when adolescence approaches. David had a mild athetosis and a moderate hearing loss as a result of kernicterus. He tested

above average in intelligence; he was well liked by his playmates. He had his own paper route. His mother described him as a reliable child. At fourteen years of age his school work began to deteriorate; he usually forgot his hearing aid, and he repeatedly failed to appear for speech therapy. A staff discussion brought out the possibility that this boy was withdrawing in this manner because of his fear or dread of assuming adulthood with a severe handicap. Adolescent counseling was recommended.

Adolescence poses other problems for both parents and the child. A frequent concomitant with any lesser degree of injury to the brain is a lack of discrimination and poor judgment. The retarded girl who has felt slighted and rejected and who is starved for affection, with her lack of judgment, is very prone to get into serious difficulty. The boy in the same situation may be unable to deal with his adolescent drives and may get enmeshed in situations beyond his control which in turn may involve him in misdemeanors or even serious crimes. Our handicapped children should be supervised and carefully counseled through this period of development. For the adolescent supervised homes may be necessary. With maturation, certain individuals may again be members at large in society. There are many who should have some type of partial guardianship or some "Big Brother" relationship throughout life. It would seem that this function might be assumed in part by the churches.

There is a large group of children, some estimate it as high as twenty percent, who function marginally for a variety of reasons; they may be emotionally disturbed, culturally deprived, neurologically handicapped, crippled, or have a borderline I.Q. They are unhappy, frustrated, confused. They have a poor image of themselves. They constitute the raw material, the great reservoir from which come delinquents, neurotics and just inadequate citizens. They are a salvagable group. Our communities fail them.

The Parents

"...the poets feign the miserable mother, Niobe, (overwhelmed with her losses) to be at last transformed into a rock, thereby to express that melancholic, dumb and deaf stupefaction, which benumbs all our faculties, when oppressed with accidents greater than we are able to bear." -- Essay on Sorrow -- Montaigne

"I never yet saw that father, but let his son be ever so decrepit or deformed, would not, notwithstanding, own him." -- Of the Education of Our Children -- Montaigne

What is it like to be the parent of a handicapped child? How does a parent accept an infant with defects? What do parents feel when they are told, "Your child is a Mongol", or has "cerebral palsy" or has "hydrocephalus"? The birth of a defective child may occur in any family. It is not limited to any class, color, creed or intellectual attainment. The birth of a handicapped child is a sad event. It is a grief that continues.

The birth of a defective child causes a bereavement (12) that in many respects is deeper and more difficult to deal with than mourning for a dead child. It is a mourning for the child that had been anticipated, confounded by the living presence of a small defective substitute not responsible for his own deficiency. As one mother said, with sobs, "We have nothing to talk about; when we meet our friends we don't know what to say, so we stay home." She then asked, "Do other parents feel this way?" These feelings are followed by feelings of guilt on the one hand and overwhelming compassion for the little defective infant, the cause of it all, on the other.

People differ in their capacity and their methods to deal with the problem. The strength, not the frailties, of parents is a recurring amazement to the staff.

A family with three normal boys lost a child with a hereditary degenerative disease at the age of seven months. A little girl was born a year or two later, and shortly after birth it was recognized that she,too, was a victim of the disease. She grew and progressed fairly well the first twelve to eighteen months, and then the slow deteriorating process began. She survived to the age of four years. She was cared for in the home, which was the parents' choice, and there she died. The parents had been instructed that the hospital would accept the child at any time. For several months before her death

she was fed by tube. She had to be suctioned frequently; a practical nurse was placed in the home to assist the parents. After death the body was brought to the hospital for autopsy. Some days later the mother stated, "She died as we wanted her to die, on a bright Sunday afternoon, at home, with her family at her bedside."

In another family, twins were born, one of which was still-born and the other had convulsions in the nursery. Johnnie, the surviving child, had microcephaly, quadriplegia, and was severely retarded. John was brought to the Child Development Center regularly, the parents participating actively. When he was four years of age, Johnnie's home was opened for boarding other handicapped children. For two or three years five Mongols were cared for in the home. Then a normal baby girl arrived and the families placed their own severely retarded child as well as the foster children ~~were placed~~ in a state hospital. This family deserves to enjoy their normal little girl.

There are other types of parents. We have children who are handicapped because of parental abuse and battering. (13) In most instances, when this has been encountered the parents themselves have been defective and should have been under guardianship. It is an inconsistency to follow the performance of trainable retarded children through school, to place them in special classes for educable and trainable, to

test them and record that they lack judgment and discrimination, and then at eighteen years of age turn them out to seek their own place in a competitive world. When they fail, we prosecute them for their crimes.

We have had parents who, when the records of the various agencies that had served the family were amassed, it ~~formed~~ presented a formidable ~~pile~~ history going back sometimes two or three generations. One mother with such a family record, after bringing a defective child to the nursery for a period of time and mingling with the other mothers, said, "This is the first time I have been treated like a human being!" Social rehabilitation is possible.

There are also parents who have deep feelings of guilt that are not revealed for several years; for instance a mother who has given away a fine though illegitimate baby and later has a premature severely handicapped child in marriage, or the mother who has an illegitimate defective infant during her marriage. The fact that these guilt feelings finally can be shared is significant and represents therapy.

There are parents who after several years of caring for a mentally retarded child at home, during which time they have been active in work with organizations for the handicapped or retarded, then place their child in an institution and drop all contact with their former intimate associates. There are other parents who have accepted the advice, probably too

readily, and too often of their physician, to "put him away". They put him away and work feverishly thereafter in all types of organizations dealing with the handicapped as if they were desperately trying to compensate for feelings of conflict.

A severely handicapped child born to a family causes grief. There is no way of "putting it away". The fact remains and the child remains. Parents must make their own decisions regarding the how and where their child is to be cared for. Professional people can counsel and give support. If families are given time, a chance to talk, to think, to exchange experiences with other parents and a chance to ask questions of medical advisors and other professional personnel, a decision without regrets can be reached. A mother is not the only one concerned about a handicapped child. A father is a parent also. A father's pride and joy in his offspring is equal to that of a mother's. A father's sorrow and grief over a handicapped child is as real as is that of a mother. A father usually has the respite away from the home during working hours. It is the mother's around-the-clock chore that wears the mother down often before the father. It is the mother also who has the most contact with the physicians and she is better informed about the child's true status. She usually comes to the realization of the chronicity of the condition and accepts it before the father. Many a father has sat with one of our staff members with his severely handicapped child and wept bitterly over the

necessity of placing the child outside the home. Often a father has stated he must do it because of his wife's inability to continue to cope with the problem in the home.

among parents of defective children

Divorce is probably as common but not more so than in the population at large. Sometimes the mother devotes her time to the handicapped child to the exclusion of all others in the home. This reaction is usually an exagerated manifestation of an already existing withdrawal from the husband and home responsibilities. A divorce, therefore, may only be accelerated. At other times, a faltering marriage may be strengthened as parents face the reality and assume responsibility. The adjustments depend largely upon the parents' ability to assume adult responsibility for the task ahead. Many physicians undoubtedly give the advice to put a child with severe defects away on the basis of their own unresolved conflicts regarding the retarded and defective.

The Siblings

"Am I my brother's keeper?" --
The Bible

What is it like to have a sister or brother who has defects, who may be retarded or even grotesque? What do you feel toward him? Does it tend to make you love more, hate more or fear more?

Children have long memories. Traumas are also recorded in the subconscious. Children are exceedingly sensitive to and perceptive of parents' feelings. The reaction of siblings to a handicapped child in their midst is a reflection of the parents' attitudes. Nowhere is the old saying more true than in a child's learning from his parents, "What you are speaks so loud, I cannot hear what you say."

In one family a Mongol was born, the sixth child, the oldest sibling being sixteen years. Upon the advice of doctors and hospital attendants, the parents placed the baby in an infants' home. At the end of a six months period, when the foster home folded, the family had a conference to discuss the fate of the sibling Mongol. It was unanimously agreed that he would come home. When the sixteen year old daughter was asked how she would feel bringing her boy friends into her home, her rather sophisticated reply was, "How do I know that I will not have one? Isn't it better to find out a boy's attitude in advance?" Children are direct; unfortunately, they learn to be devious.

The pressures and the physical labor connected with a handicapped child can be very great. No one can nurse a disabled child day and night with no relief in sight without injuring herself and leaving the home showing the effects. As noted earlier, fathers get a break while away at work.

There is only so much time and a mother has only so much to give to a family. If the pressures become too great, the siblings may suffer.

Children vary in the sensitivity with which they are endowed and, like a parent, one sibling may reach the limit of tolerance before the others do. There are other circumstances that make it desirable to remove the defective child, or children, at least temporarily from the home. The Frolton's had two retarded girls between a normal older girl and a younger boy. Nancy, at eleven, was a benign child with an I.Q. under fifty who posed no great problem in the home, but Ethel, age eight years, was aggressive and hostile toward her little brother. To the Center staff, this family of children posed such a formidable environment for the little boy that it seemed necessary to place the retarded girls temporarily away from home. The situation created a background too abnormal for a child's early healthy development.

Older retarded children have a need for being with their own kind. Many of these problems can be eased by the community sharing responsibility for the care of the children with defects.

The Community

"People need to believe that man will sacrifice for man, that he is willing to walk the wide earth in the service of man." -- Dr. Schweitzer of Lambarene -- Norman Cousins

How have communities met the needs of children with defects? In a nation of plenty do we care for our handicapped individuals in a manner appropriate to advances in other areas? May emerging countries learn from our mistakes and develop superior systems for meeting the needs of all strata of society to those we have? Do we need to change our methods?

The story of the growth of welfare work in our country has not yet been written. It will be difficult to write. In a nation of free enterprise and plenty, the dichotomy between self-aggrandizement and provision for the needy has certainly had a zig-zag course. A description of community resources and the work they do, both public and private, is impressive, but when help for a particular child with one or more problems is sought, the resources are often lacking.

The Child Development Center started around the pre-nursery school child. It was decided, however, that the children would be followed after they left the activity by having them return to the medical clinic routinely. The entire staff attends these follow-up clinic sessions, and the

social worker, educator, psychologist, physiotherapist and occupational therapist are available to answer questions, each in his own field. This means that the entire staff has maintained contact with the patients. An "open door" policy has been practised and former patients feel free to talk over problems with staff personnel at any time.

As the program has evolved and a greater number of children of school age and beyond are served, the deficiencies in the community have become more and more apparent. The child with a defect does not have only one problem; he may be a deaf child with cerebral palsy, a hyperkinetic child slightly retarded, a superior child with dyslexia, and all the children quickly develop some degree of emotional disturbance. Furthermore, families have worries ranging from economic difficulties to deaths and suicides.

This country provides many services for its children. The handicapped have not been forgotten in this planning. Presidents, legislators, humanitarians and parents have sought and obtained services for the children with defects. At the state level the Department of Public Health has a Crippled Children's program and a Maternal and Child Health Division. There is a Department of Mental Hygiene which is concerned with the emotional health of the citizens young and old, retarded and intellectually normal. The Department of Education has a special division devoted to the training of the handicapped and retarded children.

In addition, there is a rehabilitation program for those with defects, and a Public Welfare Department for those in economic need. These are public, tax supported programs; the private charities are numerous, more than one for every day of the year, ranging in interest from cancer to cystic fibrosis, and in slogans from Christmas stamps through valentine hearts to Easter seals.

With all this available, the tragic lesson has to be learned that the needs of the children and the provisions in the community do not dovetail. The services provided appear as circumscribed little islands with defined limits; the deaf school cannot take a child with cerebral palsy; the cerebral palsy school cannot take a deaf child; the superior child with dyslexia is placed in the retarded group because his reading problem lowers his score; the hyperkinetic child with a neurological deficit is placed with the emotionally disturbed even though he requires a carefully structured environment and the latter great permissiveness.

The staff worker, child in hand, knocks vainly at one door after another without finding a suitable placement. The community services are categorized to an extreme degree; unfortunately, children do not come in pure categories, they are checkered and not divisible.

Joint Attack on Community Problems

As long as we have children born with imperfections the children will have multiple problems. This situation will not change. The community, however, can change. The focus of health and welfare activities must move from agency organizations and preoccupation to patients' needs and the solution of patients' personal problems.

The basic needs of children with handicaps are the same as those of normal children. These basic needs are home, medical care, education and training, recreation and religion. Children need a home and the love and securities that go with it. Children need medical care for the best development of their physical potential. Children need education and training to reach their best mental potential. Children need recreation. If all work and no play makes a normal Jack a dull boy, it makes the handicapped child an even duller boy. Children need religious experiences. Children need preparation for work.

How can a community reorganize its services to provide these basic needs for the handicapped children?

Homes and Housing

The first basic need mentioned for a child is that of a home. The infant and young handicapped child needs a home and parents. Any departure from this can scarcely ever be a perfect substitute.

There are instances when foster homes and nursing homes have to be used. These are never a true substitute. Such homes are not permanent. They may close their doors at any time for a variety of reasons. They usually specify the ages of children that they will take. Children do not remain at one age or size. It is just as traumatic to a handicapped child to be moved from one home to another as it is to a normal child.

There may come a time in the life of certain children when the home is not the best place. Children pass through stages in their development of independence. Under three years a child needs a mother very much. Between three and six years of age he tolerates separation with increasing ease but still needs frequent communication with his parents. From six to twelve or thirteen years of age, the handicapped like the normal may thrive in boarding schools with close communication, week-ends and vacations with the family. During adolescence this tolerance of separation increases. In the case of a moderately to severely handicapped child, partial or temporary separation from the normal, with activities scaled more to his own abilities, may be a very welcome interlude for the child. If parents and siblings understand this, they may relax and also appreciate such interludes.

There is a definite need for boarding schools for a certain number of handicapped children, especially from the

age of ten up and through adolescence and young adulthood.

The teen age often is a troublesome period for normal children. The adolescent drives in children slightly retarded, and lacking in judgment, frequently get beyond the control of the family. A period in a boarding school, carefully supervised and especially designed to meet the needs of these children over a period of several years, can be very helpful. These children then may be able to assume life in the normal community. As an example, when the history of a foster child was obtained, it was learned that the mother had had a hemiplegia, convulsions and aphasia at five years of age. At twenty-nine years of age she had been married and divorced with the child of that union given to the custody of the father. Since then she had had three illegitimate children; one of these died and two were in foster homes. When this mother was brought in for examination, she still had evidence of her hemiplegia, her speech was faulty and her judgment and discrimination deficient. Who is at fault when these things happen? Guidance into maturity might have prevented these tragedies for the girl.

When the school period is passed, another type of living arrangement for young adults without the possibility of living at home should be available. For the most severely retarded, small custodial institutions provided by the state,

the churches and privately endowed, are needed. It would be preferable to have several kinds rather than only state institutions. This would create better grounds for experimentation and innovations in learning, recreation, hobbies, etc. The religious institutions also might offer a type of opportunity for participation in work which would give satisfaction to many individuals that the private or public ones could not do.

Apart from the severely handicapped, there are a large number of individuals for whom life could be made easier and more gratifying if there were homes or apartments designed for easier living. Cars have been designed to make it possible for drivers to manage even with some major handicap. Private homes have been so designed, also. The big cities or urban communities might very well design apartments without entrance stairs, with elevators that take wheel chairs, with doorways that make ingress and egress simple, and with many other devices to facilitate mobility for the crippled.

There are some children who are so retarded that they are untrainable or they are so physically and mentally defective that they cannot be taken care of adequately in any home at any time in their lives. These are the most severely involved children in the state institutions. In recent years there has been grave concern directed toward the management of the problem of retardation by state institutions. The

amassing of large numbers of defectives in one area has many drawbacks. Frequently the institutions are isolated from medical centers and not easily available for study or for teaching of medical and other professional students. It is extremely difficult for parents and often for professional people to view large aggregations of defectives with equanimity. Decentralization with better facilities at local levels has been urged . One partial solution would be for the hospitals to assume greater responsibility for the children with severe physical problems. The need for hospitalization of normal children has decreased. Hospitals might consider, therefore, the establishment, after proper diagnosis, of minimal care areas for the patients who are so physically and mentally handicapped that they need bed care. This might be done by the state contracting with local hospitals for such care. This arrangement would place the children under the same professional personnel as the rest of the hospital patients; these children would then be available for teaching purposes as a part of the population in need of medical care. The parents, relatives and friends could visit frequently, and the children could be taken home for periods of time.

The children somewhat less handicapped but still in need of total care should have hospital beds available for superimposed acute illnesses and also for a family crisis. This type of care also could be contracted for in existing

hospitals. These children might spend most of the time at home in contrast to the previously cited group in which the greater part of the time would be spent in the hospital.

For the children too severely mentally and/or physically handicapped to be in any school, but not in need of hospital care, there should be available nursing homes and/or day care centers. These should be under medical supervision rather than under the educational department as is now provided for by legislation, though not usually implemented. These children will profit more from the skills of the occupational therapists, physiotherapists and practical nurses than from educators. The latter should visit such homes on the same basis as they now do hospitalized children.

Medical Care

The second basic need of a handicapped child is medical care. This means first of all the routine medical attention that normal children receive. It covers nutrition, immunization, counseling and care of illness as it arises. A handicapped child needs more than the normal. The majority of these children are frail and more susceptible to acute diseases as well as prone to chronic conditions. Furthermore, a handicapped child is entitled to a careful medical study of his defects, and for periodic reevaluations.

Children born with defects may need the skills of almost any specialty or sub-specialty, in addition to pediatric care; i.e., the orthopedist, neurologist, neuro-surgeon, plastic surgeon, pediatric surgeon, ophthalmologist, otologist, endocrinologist, hematologist or psychiatrist.

It is essential that some physician is not only in charge of the child as a person but coordinates the sequence of the other medical repairs and treatments. The pediatrician is best qualified to assume this responsibility. In order to spare the patient and the parent, usually the mother, the hardship of travelling from office to office for care, a center in a hospital setting where the patient and doctors can meet is a logical development.

A child born with a major defect or acquiring one during his rapidly growing period needs more than a medical diagnosis. He needs a total assessment of his potential and a social diagnosis of the family and community in which he must live. Like the normal child, the one with a handicap continues to grow and develop; consequently, one examination and one assessment are not enough. Proper medical care requires regular examinations at intervals, re-assessment, counseling and placement. Facilities for such appraisal should be available to physicians in a facility not unlike the organization of a clinical laboratory with a pathologist in charge of a para-medical staff. A Child Development Center seems a

happier choice of name than habilitation or rehabilitation. Child Development indicates a study of the growth of a child with abnormalities against the known pattern of normal development.

A total assessment of the child should include:

A medical evaluation by the pediatrician, including the laboratory tests. The pediatrician should select the necessary medical consultants.

A psychological examination by a person trained in developmental psychology.

An educational evaluation, the extent of the latter depending on the age of the patient.

Hearing, speech and reading evaluations at the proper age levels.

A social diagnosis of the family and the community resources.

This type of assessment, in total or in part, should be repeated somewhat as well child examinations on normal children are done, -- frequently the first year, then at longer intervals as the child matures. Particular attention should be given to the periods of crisis; namely, at two to three years of age, when the normal child has acquired ambulation, self help in feeding, speech and toilet training; at five to seven years of age, when the acquisition of the three R's becomes important to the child; at thirteen to fourteen years of age,

or the beginning of adolescence. The child then establishes his own independence, and the handicapped child is faced with the additional apprehension regarding his ability to attain this status; and finally as a young adult seeking a job, a home, marriage and complete integration into the community.

This type of service to the handicapped and his family has proven to be exceedingly gratifying to the child himself, his family and to the staff.

Special mention should be made of the non-medical staff. It is difficult, time consuming and discouraging to work with defective children. There is so little feed-back. If a worker is isolated, and working alone with them, it leads to ennui. The hospital setting, group participation, contact with research activity, participation in education and communication inspire growth. This is the way new ideas are born. Educators, especially teachers in nursery schools and kindergartens, are trained observers of the young, and will detect the child with abnormal behavior or function quickly, but their skills are seldom utilized by either physicians, psychiatrists or psychologists. It is only in recent years that Child Development Centers using the personnel and techniques of all these specialties and disciplines have been established in Medical Centers. Even the centers in medical schools and hospitals frequently separate the children into clinics for the retarded, for the emotionally disturbed,

for cerebral palsy and for epilepsy. Habits are hard to break. Any child with either an anomaly of or an insult to the nervous system has some physical involvement, even if it is only incoordination of fine movements; he has a greater tendency to seizures if only recognizable in the electroencephalogram or behavior equivalents, and he almost invariably has some learning problem.

Education and Training

The third basic need of a handicapped child is education and training up to his best potential. One of the early discoveries in the work was that the children and the community resources did not dovetail.

Where lies the fault? No doubt in part it is a consequence of spontaneous growth in separate areas. The situation is not unlike that found in medicine when a new entity is discovered. The symptoms and signs are clearly defined, the syndrome is carefully delimited. Then follows reporting of similar cases from many areas; as knowledge of the condition increases greater variation is described and soon carrier states and frustrate forms are reported. Social structures similarly have been established to meet specific needs. They have been pressured into existence by parents, by humanitarians, by single individuals moved by personal experience. The purpose of each has been clearly defined and

the limits of service set. The time has come to widen our horizons. As long as there are children born imperfect, these children will have multiple problems, they will not come categorized. Agencies can be changed, the children will not. The focus must move away from the agency to the child, his family and environment, and the services altered accordingly.

In the infant and young child training and therapy are inseparable. Children with certain physical defects need therapy as soon as the handicap is recognized. Those with motor problems such as cerebral palsy should be started in infancy with physical therapy and occupational therapy. Deaf infants are now fitted with hearing aids and acquainted with sound stimulation as soon as the hearing loss is discovered; parents are taught to speak to them so that they early acquire lip and face reading. Blind infants can be helped by instruction to parents and attendants.

For the infants and pre-nursery school children, therefore, a hospital based program is preferable to either a school or a public health clinic. Physicians in practice are the first to be called upon when the parents become concerned. Physicians are accustomed to send a child to a hospital for further diagnosis. A center set up to assist them with the diagnosis and assessment of the child as noted earlier can be considered comparable to the clinical laboratories with a

pathologist in charge of a paramedical staff. Physicians will send a child to such a facility when they will not send him to a school or public health clinic.

There are other advantages to a hospital setting for the observation and treatment of infants and toddlers. This is the period in which the parents have the greatest number of questions; they need to have access to a facility that includes physicians readily available daily and all day long. This age period is also the time when it is most difficult to know or to predict the child's final status. It is equally important that the non-medical staff members have physicians available with whom they can discuss their observations and questions. The physicians also learn a great deal from the objective and experienced observations of skilled non-medical personnel in other disciplines.

Between three and four years of age children, except the severely handicapped, should be ready for transferal to public special classes, where their training can be continued. Even the retarded ambulatory children should be in nursery schools or the equivalent of a kindergarten between ages three or four years and eight years. It is a grave error to leave these children without training and without experienced help until the age of eight years. Children beyond three or four years of age with two or more major handicaps should have available facilities for therapy of both

handicaps. This may be done either by having school facilities so grouped that therapy is provided in a central place on the school grounds, or by providing transportation from the school to the hospital facility. The day then would be divided between academic classes and a habilitation program.

The remaining children, whether physically handicapped, retarded, emotionally disturbed, blind, deaf, aphasic, dyslexic or hyperkinetic, can be and should be accommodated in the public schools. It requires proper facilities and teachers and good communication between the diagnostic center and the school.

In a country that prides itself on providing free education for all, an unjust cost is placed on the family with a handicapped child. Public funds should provide for the education and training of children in all categories. Transportation should be considered essential to such training.

It is also essential that children with a learning problem first detected in school be referred for a diagnosis and careful assessment. Reliance on school clinics, psychological testing in schools and school counseling is not adequate. The future happiness and welfare of the child is of too great importance to deprive him of a careful study. There should be good communication between the school personnel and the diagnostic center.

Some conditions occur infrequently, notably aphasia, dyslexia and dyscalcula. For these conditions, therefore, centers, schools or classes should be provided. These classes, however, should not pose an extra cost to the family. Children with one of these defects living in a remote or isolated area, should be provided with a boarding home in a community where the facility is available. For the older age group it may be necessary to have boarding schools which combine academic education and practical training in order to prepare an individual for employment. The existing state schools, for the blind, the deaf and the cerebral palsy children, should be re-appraised to determine whether their functions need to be altered. With increased facilities to educate and train "normal" blind and deaf children in local communities, a better function for a state school would be specialized services for the multipli-handicapped. As examples of these problems the following two cases are discussed briefly:

Robert, with a severe communication problem characterized by speech which was a jargon not understandable by anyone but himself, was diagnosed at age six as aphasic. He attended public school where he received some speech therapy once a week; he was passed from one grade to another without improving his method of communication. When he was first seen at our Center he was fifteen years of age; he had a

handsome physique without stigma; his intelligence tests placed him in the normal range; he was well adjusted with his peers in the neighborhood; his family was realistic about his handicap but felt completely frustrated in getting help for the child. The staff, too, was frustrated. The boy needed to acquire enough understandable language to hold a job; he needed to learn skills in some trade where the necessity for speech was minimal. The parents had no higher ambition for him than this, but there was no class or school for the intensive training of a child with this type of problem in his home area. He was sent half way across the continent at the cost of five to six hundred dollars per month, a sum the parents could ill afford. At this school he learned cooking, a skill not requiring much speech. He acquired enough command of words to be understood. He should be self-sufficient.

Timmy, at age fourteen years with an intelligence quotient in the superior range, had been unable to acquire reading skill; he was dyslexic. He had been retained in classes; he had been tutored; he had had psychotherapy, but he could not read. Seven years of exposure to failure in an intelligent, sensitive child is exceedingly traumatic. With all the various methods of transmitting information that are available, from Braille to recordings, should a child be exposed to this type of humiliating failure for years? There is no community facility to help him.

Training for Jobs

Children with an abnormal genetic pattern, a foetal insult or an injury to the nervous system in early life are very apt to have either some degree of mental retardation or a problem in learning or an emotional overlay that distorts his self image unless he and his family have wise counseling. Many of these children cannot become proficient scholars. The academic ability can be very well determined by eleven or twelve years of age and training from then on should be oriented to useful work. Only in this way can a child's incentive and motivation be maintained. One of the most devastating experiences our children with learning problems suffer is eight to ten years of academic failure. The type of training made available to children with defects must be diversified to meet the needs of many different types of individuals. There is no way of massing these children into large groups and presenting them with a uniform program.

The schoolroom experience should be a continuum with jobs in the community or with a place in a sheltered workshop either as a separate institution or as a part of an industrial plant.

Handicapped children have assets. Richard Scammon once said, "To achieve you either must have superior physical energy or be handicapped so that you are not distracted by the frivolities of life." The person with limited physical ability

does often apply himself more diligently to his task; he has learned self-discipline and he can and does render more dedicated service than the normal individual. A community's plan, therefore, for handicapped individuals should start as soon as a child is recognized as having a defect and be continued throughout a lifetime unless the defect is wholly remedial.

The diagnostic services and the community services should set their sights on certain goals for handicapped children. As stated earlier, a growing organism is constantly undergoing change. If the normal or genetic potential of growth has met with interference, we have abnormal development with which to deal. Although we have learned considerable about the normal patterns of growth, knowledge about the abnormal or deviates is largely lacking. Furthermore, it will always be much more difficult to acquire such knowledge because injury can introduce a host of variables into the pattern, and each child practically will need individual evaluation. This is the reason that a diagnostic and assessment center is of such importance for the continuation of the study of the individual and the repeated counseling with alteration of plans as indicated. The aim, naturally, is to restore the individual as nearly as possible to functioning in a normal manner in the community; this refers to school and preparation for independent living in its broadest meaning. In reality, however, many an individual, even with the aid of the best known medical skills and the wisest counseling, must settle

for a lesser goal than this. The increased understanding in industry, the professions and other work areas, of the assets that the handicapped bring to the field, is and will make it possible for a larger number to find employment. These assets as mentioned earlier are devotion, application, faithfulness, self-discipline, lack of distraction and fragmentation of his talents.

For the more severely handicapped who even with changed attitudes will not be able to fit into the stream of work life, part-time work or full-day work in a limited way has much greater application than has been made use of to date. Bringing certain work to the individual, instead of the individual to the job, should be further explored, in all areas. In large industries it may be possible to set up areas, or an area, to which certain work is assigned or brought, and this serve as a sheltered work-shop within the plant. More and more is being learned about the abilities of handicapped individuals, and the range of work may well increase.

The individuals with even greater limitations are entitled to use those faculties they have for pleasures, hobbies or any practical application to which their endowments can be put. Let's give those who only sit and wait that limited chance to serve.

Our culture is changing, shifting and aging. Communities, small ones, or divisions of large urban ones, could be made more self-sufficient, if the part-time man- and woman-power were utilized efficiently and practically and with dignity. There is greater satisfaction in life if a day is divided into some work, some recreation or amusement, and some meditation and rest. Our patterns should not necessarily mean an eight-hour day five days a week for all people. The aged, the handicapped, and the semi-invalided may have different schedules. There should be training programs for useful services in the local area scaled to the interest and ability of the individual and the many needs.

For women, there are baby-sitting, extra hands in child care centers for both normal and handicapped children, sewing and mending in all its varieties. In a culture as mixed as ours, it would be interesting to cultivate native crafts of the various countries represented in the community.

For the men, there are gardening, repair work and crafts. If man-pools were available and skills made known, there could be a regular exchange of small part-time services.

Our educational systems need a great deal of revision in many areas to prepare the handicapped and limited people in the way of life described. Education is designed toward serving the average or great mean. Considerable emphasis has been placed on integration of the handicapped with the normal. Too

often the pro's of this method have been emphasized and the voice of the con's at the realistic level of the classroom has been muffled. The attempt to integrate all handicapped children into the normal schools without adequate preparation and continued help is like asking all the players in a symphony to play their instruments without a conductor or director to produce harmony. Children with defects cannot be turned into the turbulent stream of young lives and be expected to survive without preparation and assistance. This type of help is realistic and does not result in either over-protection or lack of faith in the child's potential.

There is a great need for experimental schools where the learning process may be studied by independent imaginative educators in close cooperation with pediatricians, neurologists, psychiatrists and psychologists.

Recreation

"On Sundays I would find my perch on the wall near the entrance gate to the sanitarium and would watch the healthy people... as they walked up the hill to the bus... they owned the miracle of being able to leave when they wanted to." -- Ibid.
Schweitzer -- Cousins

"The outside world was something of an unreality. We longed for it but it was like pressing our noses against the windowpane of a non-existent tomorrow." -- Ibid.

Recreation is another basic need for handicapped children. Very little thought has been given to recreation,

pleasure or hobbies of the handicapped. If any recreation has been given it has usually been limited to two weeks camping experience. When working with children, especially with the young, the joy of play, and the same impishness that is seen in normal children is so obvious. Unfortunately, as time passes, the spontaneous smile and the chuckle of amusement disappears. Similarly, the little child, before frustrations have blunted his desires, shows great eagerness and strong impulses to try any new thing. It is necessary to capitalize on a child's readiness, otherwise the optimum moment passes and one may not be able to re-awaken the same interests.

Very severely handicapped children, with extreme limitations, may still enjoy music. Music has great variety and many methods of presentation, such as records, television, radio, live, accompanied by dancing, ballet and opera. Why should not a child whose only enjoyment may be music have a chance to learn, up to his capacity, music in its many variations?

Painting is another activity that has at some time or in some way intrigued almost all of us. It is noteworthy that severely handicapped individuals have painted holding the brush by the toes, in the mouth or attached to a headpiece. Childhood is not complete unless at some time hands have been dipped in paint and splashed over a canvas.

Imagine the joy of a severely crippled child being strapped to a saddle for a canter around the green, or the blind child climbing a tree! Other activities that can be enjoyed are ball games, merry-go-rounds and swimming. Dancing can be participated in to a degree by the most severely handicapped youngsters. In some cultures the dance rhythms are limited to eye, head, finger or hand movements. There is practically no child who cannot participate to some degree,--even watching others dance may be a joy. Isn't it to most of us?

The recreation centers afford an unusual opportunity for a child to develop a hobby and for the staff to observe and note the child's talents. For those individuals who are going to be too handicapped to be self-sufficient, a hobby can be an absorbing activity, and with the kind of concentration the handicapped often apply to a task, some valuable contribution may also result. The handicapped and retarded should have this opportunity and such pleasure as they can be given. VanGogh is an example of a severely handicapped person who achieved enduring fame. Yes, some are "crackpot" geniuses! Year round recreation is essential.

The Churches

A little boy, as the plane took off
into the air, said, "Are we higher up
than God?"

Religion is a basic need of children. The churches have done a great deal to promote both education and health.

It is curious that the handicapped and the retarded particularly somehow seem to have been generally overlooked. Sunday is such a welcome break after six days of monotony. To dress up in your Sunday best and go to Sunday School has a nostalgia for many grown-ups. The singing, the ritual and the formality are appealing to children. The festive days, such as Christmas and Easter, have particular significance, and children's programs can add much to a child's pleasure.

Only those who have experienced the comfort of faith, the release of anxiety through prayer and meditation, know that children, especially those restricted in every way else by a crippled body, can enjoy to feel that the spirit is free even if the body is not. Upon admission to a state institution, one child's comment was, "At last I can go to church."

There are many other services the churches could provide, such as day care centers, temporary or permanent homes.

Guardianship

There are many ways beside the very simple means of Sunday School, church services and religious education in which the church can serve these children. Many children, young adults as well as adults and the aged, need guardianship. One of the inconsistencies we practice is to assess the children who are failing and note that they lack discrimination and judgment, yet at eighteen or twenty-one years we expect them

to be responsible citizens. When they fail in moments of stress, in little or big ways, they have been condemned and even executed. The church could be a big brother to some of the less severely retarded, even throughout life.

Equipment and Transportation

In addition to these five basic needs, children with handicaps often need special equipment. Many need braces, crutches and wheel chairs. The cost of these items can be a real burden to a family. Provision should be made for a central place to obtain such equipment, for the repair and exchange of it as the child grows or outgrows the need for it.

The handicapped child also needs more help than the normal with transportation. The schools in general provide transportation for their crippled children but transportation is also needed for pre-school children and for other than school purposes, such as to recreation centers and to therapy centers.

Professional Training

"In education, for example, whenever a proposal is made that looks toward increased intellectual effort on the part of the students, professors will always say that the students cannot do the work. My observations lead me to think that what this usually means is that the professors cannot or will not do the work that the suggested change requires. When in spite of the opposition of the professors, the change has been introduced, the students, in my experience, have always re-

sponded nobly." -- The Great Conversations

In the course of our previous discussions the work of many different kinds of professional people has been referred to,-- physicians in many specialties, psychologists, social workers, educators, speech therapists. How well do our schools and colleges prepare their students for work with the handicapped? Are we not still isolationists in our training programs? Physicians, particularly, are prone to remain aloof, and sometimes they are even disdainful or derrogatory, toward the work of others in related fields.

The history of Medicine goes back to medicine men, magic, superstition, barber surgery, cupping and bleeding, as well as to Aesculaepeous, Hippocrates, Galen and Hygeia. This should not be forgotten.

In Medicine, as in all branches of knowledge, adaptations occur. Like the organism itself institutions grow irregularly. Advancements are made in one area at one time or during one generation and in another the next. The final development may show little or no relationship to its origin. There is, however, a sub-strata of fluid knowledge out of which emerge at intervals new ideas. When these are usable and acceptable, an entire new discipline of knowledge may evolve. Sometimes it is necessary to eradicate entirely and rebuild as knowledge increases. In all the major disciplines that have

survived, there is an enduring core of principles. This is true in Medicine. At times rapid growth obscures the basic principles upon which the science was founded, but invariably when this happens voices are raised; there may be a time of turmoil and confusion as adjustments take place, and then equilibrium is again established.

The present state of Medicine is one of explosive acceleration in many areas at once,-- genetics, chemistry, virology, immunity, antibiotics, and so on. It behooves some in the field to keep the focus on the organism MAN as a unit and his reaction in and to his environment. It is not enough to analyze the body chemically, to mend its broken parts or even to replace missing portions. In one of the newest fields, Space Science, the intensive study of nuclear fission, mathematics and chemistry is coupled with the study of MAN in orbit. In Medicine, the study of the cellular structure and function by the research scientist and the observation of the clinician should have this same relationship.

Medical Schools in the training of scientists in the health fields must bring about this type of equilibrium. A physician entering the practice of medicine must not only be well versed in the basic sciences that are pertinent to his profession, but he must also understand his patients and their total needs as these pertain to optimum health. In the prac-

ticing field the physician has many helpers and it should be a part of medical training to help doctors to understand the roles of, and how to utilize the skills of, the paramedical and the non-medical staffs.

In other disciplines, it is equally important that a thorough knowledge of his own specialty is combined with an appreciation of the limitations of a single point of view and the role of the other disciplines. When this is not accomplished in the care of our children, the results are discordant. The physician is the logical person to direct the group. The handicapped child has recurrent health problems and all the other disciplines must go back to the basic problem and get their cues from the physician in charge.

It is increasingly apparent that it is important to have the health sciences grouped about the Medical School and to have training in the various fields related to one another and not set apart in different locales and with independent staffs or with piecemeal approaches to the child.

In the study of Homo Sapiens where do the various sciences and disciplines meet? The point of contact which appears most natural is growth and development of the young organism, before it has differentiated completely into more distinct component areas of knowledge and performance.

Curiously in Medicine embryology has been relegated to the pre-medical studies and the teaching of diagnosis and

and therapy based almost entirely on the adult, as if the moment the infant is born he is then a miniature adult who needs only to increase in size. Fortunately for Medicine, the basic sciences are emerging and are revealing staggering new insight into the structure and function of man. This newer revelation of the complexities of man will return us to the study of the beginnings of growth and development, and the factors that influence the form, structure and function of the organism. Disease will then be considered as deviation from the normal. The study of anatomy can no longer be limited to a gross and microscopic structure of organs; it will be combined with a study of function, chemistry in all its variations, hormones, enzymes and genes.

The study of the science of Homo Sapiens can be visualized as starting in the grades and continuing, with students branching off at various times in their studies, depending upon major interest and capacity. Some may have their curiosity aroused and continue the study of anatomy, or bacteriology, or chemistry; others may find the science of sociology or of psychology to be the one in which he wishes to remain.

As certain members pursue this study there will be those who wish to practice the healing art in all its many variations and with the assistance of the experts in every field. Man's behavior will always captivate the imagination and his evolution has not ceased. It will surely take major

development in Medicine to attain this goal.

Somewhere in the course of training in Medicine or other fields related to human welfare, the student must learn to resolve his own feelings and reactions toward his fellow men who are born imperfect or become defective. Man along with animals of other species tends to reject or even destroy the defective. The human side of us, that which makes us humans, can be rated by our acceptance of and rendering assistance to those who are handicapped, retarded or mal-formed.

Prevention

Tightening Up Our Defenses

"The gardener said that a tree of this kind took two hundred years to reach maturity. 'In that case,' said the marshal, 'there is no time to lose. Plant it today'." -- The Great Conversations

Medicine has come a long way in the battle against disease. This has been accomplished by many and varied means, public health measures, immunizations, surgery, anaesthesia, antibiotics and also by education and improved economies. The present accelerated speed of discovery promises continued victories against the still unconquered maladies of man. Are we, in our quest for the dramatic, omitting some of the simple and obvious preventive measures? There is nothing as humbling to

a physician as a disease induced by himself. Many such tragedies have and are occurring.

Drugs

Drug-induced pathology should come first on the list of iatrogenic diseases. The list of these conditions was long, before Thalidomide produced thousands of malformed babies. There was blindness from excess oxygen, deafness from hydrostreptomycin, deaths from chloromycetin; there have been others and there may be many, many undiscovered or unrecognized sequelae to the indiscriminate use of drugs. To those of us in the pediatric field it is especially disconcerting that so little thought has been given to the peculiarity of the young or growing organism to drugs. This defect in our thinking stems in part at least from our failure to study adequately embryology, and foetal and child growth. It is basic to prevention in this area of therapeutics that the young cease to be considered as miniature adults. Drug prescribing cannot be done on a mathematically reduced basis.

Pharmacists and pharmaceutical firms should have the same code of ethics as physicians. As physicians, have we not sold our birthright for a mess of pottage when we depend on advertising of drug firms to support our Journals, entertain us at medical meetings, pay for graduate education

and dole out money for research? Is it right that we encourage the type of competitive enterprise that fosters taking risks with human health? Is it correct to place this additional cost burden on our families?

Para-natal Hazards

One of the earliest emphases in both public health and private medicine was on maternal care. A great deal of progress has been made as mortality and morbidity figures show. Great emphasis has been placed on prevention of prematurity. Prematurity is a hazard but there are other factors that introduce hazards to both the premature and the full-term infant. A recent look at over six hundred twin infants and their birth records showed that only one death could be attributed to trauma, but over one hundred of the children had need for oxygen. Drugs and anaesthesia contribute to newborn distress. Newborn distress has a high correlation with later problems of children, especially in the learning areas and the now termed neurologically handicapped.

There are other factors contributing to crises of birth,-- particularly important are blood incompatabilities. Careful observation and prompt therapy have saved many children from permanent sequelae, but vigilance must be maintained.

Surgical Risks

Remarkable advances have been made in both surgical techniques and in anaesthesia. It is difficult to say which of these has contributed the most to improve recovery from surgical procedures. It must be noted that neither the surgeons nor the anaesthetists have had adequate training in pediatrics and the unique risk posed by a growing organism subjected to a stress well tolerated by an adult. The risks of surgery are many,-- drugs, hypoxia, prolonged anaesthesia, shock, cardiac arrest, dehydration, over-hydration, emotional trauma. Anaesthetists and all surgeons, regardless of the subspecialty that is practiced, if they deal with children, should have training in growth and development and the risks peculiar to the young.

Infection

Although immunization and antibiotics have greatly reduced and almost eliminated many infections, not all morbidity has been prevented, and in some previously fatal diseases the incidence of handicap has increased. Direct infection of the nervous system obviously poses the greatest hazard. The danger is increased the younger the child, the greater the duration of the disease before treatment is instituted, and the type and severity of the infection. Very few children in the first one to two years of life escape without sequelae from such diseases as encephalitis and meningitis. Many older children

show varying degrees of temporary or permanent impairments. Prompt diagnosis and adequate treatment constitute the best preventive measures when immunization is not possible. The children who have had a central nervous system disease should be carefully assessed and parents and schools counseled until the child's functions are as nearly as possible restored to normal. Infections, as is now well documented, at least in German measles, may seriously handicap the foetus. Immunization for a disease that has been considered mild must therefore be considered.

Infections other than those of the central nervous system may also be a hazard. The dehydration and toxicity of diarrheas often cause central nervous system damage. The toxins of other organisms, particularly pneumococcus and staphylococcus, may also impair the brain. It must not be forgotten that the drugs administered for infection may also be harmful. Deafness from hydro-streptomycin is an illustration. Again, in the diseases for which we have no immunization, prompt diagnosis and adequate safe treatment is the best recourse.

Poisoning

Lead, the classic poisoner, is still a hazard even though many sources of the past have been eliminated. The controversial "Silent Spring" has alerted us to many of the

dangers latent in the food we eat whether frozen or canned, the detergents with which we wash our dishes, the sprays in and out of the house and the poisons falling or windblown uncontrolled from the atmosphere. The home adds to the above hazards those of candied aspirins, parents' tranquilizers and grandma's sleeping pills, to mention but a few of the household dangers.

Bodily Injury

The prevention of both poisoning and accidents has been vigorously supported by the Academy of Pediatrics, the National Safety Council and by other national organizations. In the younger age group poisoning is the more common accident. Bodily injury occurs more frequently in the older child. Skill fracture, with or without subdural or epidural hematomas and without accompanying gross hemorrhage, still has a high incidence of sequelae. Again, the younger the child the greater the hazard. The children who have had head injury should be followed with electroencephalograms, psychological testing and educational evaluation and counseling until the possibility of any even subtle sequelae has been determined.

Inborn Errors of Metabolism

As more diseases due to error of metabolism are discovered it becomes mandatory that these conditions be de-

tected early and when therapy is available the child be given such benefit as therapy provides at the earliest possible moment. At present the known diseases that benefit from early recognition and treatment are cretinism, phenylketonuria and galactosemia. In our experience these diseases like other birth defects are very often associated with other deficits and treatment may greatly improve the condition but the child may still not attain normal development in all respects. This knowledge is important. When it is not known, defects may be attributed to either inadequate or late treatment, which may not be the case.

Genetics and Youth Counseling

The trend to introduce science early in the educational program is increasing the sophistication of our youth. The teen-ager may be concerned about the potential of a hereditary disease in the family. This may be one of the most hopeful means of partially controlling the severe metabolic and chromosomal diseases. The general emphasis on population explosion may make voluntary control more desirable. To those who have no children or should not bear them, emphasis on the many ways in which our children need help, such as by adoption, foster home care, in education or recreation, should in many instances be an adequate substitute for the risk of producing a defective individual.

Youth counseling should aid in other ways. There is an optimum time for child bearing. The young should know this. If parental discipline breaks down, the self-discipline of youth should be encouraged. Early counseling should diminish the use of alcohol, tobacco and drugs, and other habits that may be injurious to their health and that of the offspring. Faith in youth is important.

Although future research may reveal new methods of preventing defects, the past experience indicates that new discoveries bring new problems. A great deal can be accomplished now with the knowledge we have if we all will tighten up our defenses.

Redevelopment

Is there need for any great change in our care of children? When a housing division has become antiquated, the plumbing out-moded, or termites have undermined the structure, it is customary to remodel or tear down the old and rebuild the area. Institutions and agencies, like houses, get out-moded, and when they are, redevelopment is as important in the latter as in the former. What are some logical changes that will improve the health programs for our children?

Indigency

In the first place, it should be self-evident that there should be no indigent children. There may be indigent parents, but our children should not suffer discrimination in health care because of the family's inability to pay for it or indifference regarding it. If children's health needs are provided from public funds, the federal, state or local agency should contract with the existing pediatric departments for their services. Children should have the health care that they need irrespective of the families' financial status.

Hospitalization

The aging population, with increased emphasis on geriatrics, has changed hospitalization to such a degree that there should now be more hospitals exclusively for adults, and the children provided for according to their peculiar needs in separate hospitals or wings of only a few general hospitals. The emphasis by Accreditation Boards, Hospital Boards, Administrators, Staffs and Medical Schools on four clinical departments, Medicine, Surgery, Obstetrics and Pediatrics, has become a way of thinking that needs to be changed.

In contrast to adults, and particularly the aged, children are hospitalized infrequently and for very short periods of time. Even the children with chronic diseases

are cared for in homes and in hospital ambulatory services. As long as all hospitals, or nearly all, have a Pediatric Department set up on the same basis as the other clinical services, pediatrics suffers. Occupancy is low. The department, by the standards of the other departments, is on the debit side. Furthermore, it becomes extremely difficult to establish an adequate training program for accreditation. This means the children get the short deal. In other situations, such as rehabilitation programs, specialty clinics in hematology, endocrinology, neurology, hearing centers, if designed for adults and children, the children again get the short deal. Orientation is toward the majority. The children's problems in any of these situations vary markedly from those of adults. If we are going to have proper services for our children this type of fragmentation must be eliminated. Our children must be grouped together where professional personnel trained in pediatrics, and in development of children, may concentrate on programming to meet childhood's needs. This will mean a re-orientation of medical thinking in Medical Schools, Hospital Centers, Accreditation Boards and Medical Societies, but it must come about if we hope to give proper care to the children and well rounded training to professional staffs.

A Child Development Facility

A division within the Pediatric Department for the total assessment of the child, medically, educationally, emotionally and socially, either in a Child Development Center or a similar facility, should be as essential as is the clinical laboratory, with a pathologist in charge of a para-medical staff. Such a diagnostic facility should be open to all physicians for referral of patients regardless of the patient's financial status. It should be adequately staffed, properly financed and administered.

Risk Registry

In order to detect minor deviations early and also to increase the skill in diagnoses, obstetrical departments, newborn nurseries and pediatric services both medical and surgical, should keep a risk registry. Obstetricians have a great deal of information about maternal health that may jeopardize the foetus; diabetes, hydramnios, German measles, age, incompatability, previous lost pregnancies, bleeding, threatened abortion, familial hereditary diseases, and so on. Some of these pose a greater risk to the foetus than others; the hazards could be given ratings. Similarly in the newborn nursery the risks are known. Babies may be born prematurely, they may be small at birth even at term, they may be born

with congenital anomalies; regardless of size or age they may be exposed to distress at birth, to blood incompatability, to hemorrhage, to trauma, to infection or a combination of any two or more of these stresses. These risks also should be given ratings. Infants and children undergoing surgery may have periods of apnea, they may have cardiac arrest, excessive blood loss or dehydration. Skull fractures and concussions are risks. Meningitis, encephalitis, dysentary, severe toxemia, and even the drugs used for therapy may have ill effects on the central nervous system. These diseases in infancy and early childhood particularly are a risk.

Community Responsibility

Practicing pediatricians and physicians serving children must assume leadership in community planning for children with handicaps. All the health agencies, the school programs for education of the handicapped, the homes for abandoned children, nursing homes for the handicapped, and adoption programs all need medical participation. The final authority in health is the doctor. In planning for all the still un-met needs for the handicapped, a physician's counseling is essential.

Research and Practice

Instead of attempting to combine the practice of medicime, in other words, service with research, the clinician and the research scientist should be colleagues. The placer

gold in research has been fairly well exhausted; basic research now requires special knowledge, instruments, techniques and time. It is unrealistic to expect the clinician to do both research and practice clinical medicine. It is equally unrealistic to expect the laboratory man to have the skill and art of the clinician. Clinical observations, however, are of extreme importance. If the practicing physician had a research scientist as a colleague to whom he could bring his observations and his clinical material there would be a greater chance to find break-throughs in our ignorance.

Education and Service

In teaching, similarly, undergraduate students need the undivided attention of a teacher. The patient needs the undivided attention of his physician. This ideal could be achieved if the clinician and the teacher were colleagues. The clinician could keep the instructor supplied with the number and kind of patients he and the students needed for the lesson while he continued the service part of the clinic. This method has been used very successfully in the Child Development Center with other disciplines, namely nursing, public health, educators, physiotherapists and occupational therapists.

Epilogue

Children are important. They are our greatest asset. They all should have an opportunity to develop to their greatest potential. This nation has and is doing many things to help children attain this goal. In the last several years concern for the handicapped has come to the fore. The money and the know-how to improve the lot of the child born imperfect or injured later is available. It will take major re-development in the health and social sciences to accomplish the goal. Let's start now!

BIBLIOGRAPHY

1. Thelander, H. E. MD. Childhood Ecology Seminar. Journ. Ped. Vol. 44 No. 3 pp 304 306. March 1954

2. Thelander, H. E. MD. A preschool Cerebral Palsy Program. JAMWA. Vol. 9. No. 5. pp 157-159. May 1954

3. Thelander, H. E. MD. and Phelps, Jane K. BA. Programming for Children with Neurological Deficit. Journ. Ped. Vol. 58. No. 3 pp 389-391. March 1961.

4. Phelps, Jane K. and Thelander, H. E. MD Letter to the Editor, Journ. Ped. Vol. 55 No. 5 pp 672-674. Nov. 1959.

5. Kroeber, A. L. Anthropology Today Review Chicago Press 1953.

6. Wolff, an Anatomist in 1759 told his audience, after looking at cells under magnification, that there was not a miniature human in the cell.

7. Thelander, H. E. MD. Observations on the Development of Brain Damaged Children. Cerebral Palsy Review. Nov.-Dec. 1959.

8. Thelander, H. E. MD. Phelps, Jane K., Kirk E. Walton, MA. Learning Disabilities Associated with Lesser Brain Damage. Journ. Ped. Vol. 53 No. 4 pp 405-409, Oct. 1958

9. Spock, Benjamin MD Baby and Child Care. Pocket Books, Inc. 1946

10. Holt, L. Emmett Jr. Baby and Child Care. Appleton 1957.

11. Gesell, A. MD. and Ilg,F., The Infant and Child in the Culture of Today. Harper Bros. New York. 1943.

12. Solnit, Albert J., Stark, Mary H., MSS. Mourning and the Birth of a Defective Child. Psychoanalytic Study of the Child. Vol. XVI pp 523-537. 1961.

13. Kempe, C. Henry, Silverman, Frederic N., Steele, Brandt, F., Droegemueller, William, Silver, Henry K. The Battered Child Syndrome. JAMA Vol. 181. No. 1. pp 105-112. July 1962.

The following list of books in the Hospital Library show some of the steps in the evolution of the concept of total child care.

Gesell, A. et Al. Child Development and First Five Years. Harper. 1940.

Gesell, A. and Armatrude, T. Developmental Diagnosis. Paul B. Hoeber, N.Y. 1941.

Ribble, M. The Rights of Infants. Colombia Univ. Press. N.Y. 1943
Aldrich, C. Anderson and Aldrich Mary M. Babies are Human Beings. Macmillan. 1946.

Spitz, R.A. Hospitalism. The Psychoanalytic Study of the Child. II 113 1946.

Piaget, Jean. The Origin of Intelligence in Children. International Univl Press N.Y. 1952.

Bowlby, J. Maternal Care and Mental Health. World Health Organ. Monograph. 1952

Andre, Thomas, Yves Chesni and S. Saint-Anne Dargassies. The Neurological Examination of the Infant. National Spastic Society. London. 1960.

Hills, Carole P. Spector, R.G. The Nerve Cell. The Spastic Society. William Heinemann Med. Books. LTD. 1964

Illingsworth, R.S. Development of the Infant and Young Child. E and S Livingstone LTD. Edinburgh and London. 1960.

Riessman, Frank. The Culturally Deprived Child. Harper and Brothers. N.Y. 1962.

Patton, Robert Gray and Gardner, Lytt I. Growth Failure in Maternal Deprivation. Charles C. Thomas. 1963.

Parallel with preceding list are books related to abnormalities whether due to hereditary factors, injury, or disease. Some of the books in this category are listed below.

Strauss, Alfred A., and Lehtinen, Laura E. The Brain Injured Child. Grune and Stratton. 1947.

Rusk, Howard A., Living with a Disability. Blakiston. 1953.

Martmer, Edgar E., The Child with a Handicap. Charles C.Thomas. 1959.

Crothers, Paine. The Natural History of Cerebral Palsy. Harvard Univ. Press. 1959.

Denhoff, Eric. and Robinault. Cerebral Palsy and Related Disorders. Mcgraw and Hill. 1960.

When Poliomyelitis waned, The National Foundation and students of unsolved mysteries directed attention to congenital anomalies. A sampling of the vast literature appearing concerned with these abnormalities follows.

Hsia, David YiYung. Inborn Errors of Metabolism. Year Book Pub. 1959.

Congenital Malformations. First International Conference. J.B. Lippincott. 1960.

Congenital Defects - Papers and Discussions presented at the First Inter-American Conference. J.B.Lippincott. 1963.

Congenital Malformations - Papers and Discussions. Second International Conference. International Med. Congress LTD. 120 Broadway N.Y. 1964.

Lennox, William Gordon. Epilepsy and Related Disorders. Vol. I and II. Little Brown and Co. Boston and Toronto 1960.

Livingston, Samuel Living with Epileptic Seizures. Thomas 1963.

The retarded have been with us since early history, but the physician has tended to turn his face the other way. Recent presidential action is changing this attitude.

Masland, Richard L ., Sarason, Seymour B., Gladoin, Thomas, Mental Subnormality, Basic Book New York 1958.

Heber, Rick and Stevens, Harvey A. Mental Retardation - A Review of Research. University of Chicago Press Chicago and London 1964.

In other disciplines as in Medicine small beginnings have gradually expanded and a great deal is known regarding ways and means of helping the child less than perfect.

Psychology

Kanner, Leo. Child Psychiatry. George Banta Co. 1957.

Jersild, Arthur T. Child Psychology. Prentice-Hall, N.Y. 1954.

Psychoanalytic Study of the Child. 1964.

Satir, Virginia M. Conjoint Family Therapy. Science and Behavior Books. 1964.

Witmer, Helen L. and Kotinsky, Ruth. Personality in the Making. Science and Behavior book 1964.

Communication

Freud, Sigmund. On Aphasia. International Univ. Press. N.Y. First pub. in 1891.

Cass, Marion T. Speech Habilitation in Cerebral Palsy. Columbia. 1951

Jordan, Raymond E. and Eagles, Eldon L. Hearing Sensitivity and Related Factors in Children. Laryngoscope. St; Louis, Mo. 1963.

Disorders of Language. Ciba Foundation. 41 Portland Place. London 1964.

Money, John. Reading Disability. Progress and Research Needs in Dyslexia. Thomas 1957

Visual Handicaps

Hathaway, Winifred. Education and Health of the Partially Seeing Child. Colombia Univ. Press 1954.

Lowenfeld, Berthold. Our Blind Children. Charles C. Thomas. III 1956.

Spencer, Marietta B. Blind Children. Lund Press Inc. 1960.

Education and the Handicapped.

Baker, Harry J. Introduction to Exceptional Children. MacMillan. 1954.

Ingram, Christine P. Education of Slow Learning Children. Ronald Press. 1953.

Gallagher, James J. The Tutoring of Brain Injured mentally Retarded Children. Charles B. Thomas 1960.

Cruickshank, William M. et al A Teaching Method for Brain Injured and Hyperactive Children. Syracuse 1961

Clough, M.F. Teaching the Slow Learner. Philosophical Library. 1961.

In the Fields of Physiotherapy, Occupational Therapy and Recreation there also are books appearing.

Rachel Carson Silent Spring Houghton Meffin Co. Boston 1962

Bobath K. and Bobath B. An Assessment of the Motor Handicap of Children with Cerebral Palsy and of their Response to Treatment. Occupational Therapy Journal. London. pp 1-16. May 1958.

Willard, H.S. and Spackman. Occupational Therapy. Lippincott, Philadelphia. 1963.

Pomeroy, Janet. Recreation for the Physically Handicapped. MacMillan 1964.

Two books pertinent and interesting in other fields are:

The New Knowledge of Dog Behavior. by Clarence Pfaffenberger. Howell Book House, Inc. 1963.

There are also books that are of special comfort to the patient, parent or family:

Carlson, Earl R. Born That Way. John Day 1941.

Buck, Pearl The Child That Never Grew. John Day and Co. 1950.

Brown, Christy. My Left Foot. Secker and Warburg. 1954.

Kirk, Samuel A. Karnes, Merle B., Kirk, Winifred D. You and Your Retarded Child. MacMillan 1955.

Lewis, Richard S. Strauss, Alfred A., Lehtinen, Laura E. The Other Child. Grune and Stratton. N.Y. 1960

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Kanner, Leo. Child Psychiatry. George Banta Co. 1957.

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Jordan, Raymond E. and Bagles, Eldon L. Hearing Sensitivity and Related Factors in Children. Laryngoscope. St. Louis, Mo. 1963.

Disorders of Language. Ciba Foundation. 41 Portland Place. London 1964.

Money, John. Reading Disability. Progress and Research Needs in Dyslexia. Thomas 1957

Palmer, Charles E. and Kidd, John W. Speech and Hearing Problems. Charles C. Thomas 1961.

Spring et al. Hearing Therapy for Children. Grune & Stratton. 1955

Schuell, Hildreth. Aphasia in Adults: Diagnosis, Prognosis and Treatment. Hoeber. New York 1964.

Berry, Mildred F. and Eisenson, Jon. Speech Disorders: Principles and Practice of Therapy. Appleton N.Y. 1956.

Myklebust, Helmer R. Auditory Disorders in Children. Grune and Stratton. N.Y. 1954

Visual Handicaps

Hathaway, Winifred. Education and Health of the Partially Seeing Child. Colombia Univ. Press. 1954.

Lowenfeld, Berthold. Our Blind Children. Charles C. Thomas III 1956.

Spencer, Marietta B. Blind Children. Lund Press Inc. 1960.

Education and the Handicapped.

Baker, Harry J. Introduction to Exceptional Children. MacMillan. 1953.

Ingram, Christine P. Education of Slow Learning Children. Ronald Press. 1953.

Gallagher, James J. The Tutoring of Brain Injured Mentally Retarded Children. Charles B. Thomas 1960.

Cruickshank, William M. et al A Teaching Method for Brain Injured and Hyperactive Children. Syracuse 1961

Clough, M. F. Teaching the Slow Learner. Philosophical Library. 1961.

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Willard, H.S. and Spackman. Occupational Therapy. Lippincott, Philadelphia, 1963.

Pomeroy, Janet. Recreation for the Physically Handicapped. MacMillan. 1964.

Two books pertinent and interesting in other fields are:
The New Knowledge of Dog Behavior. By Clarence Pfaffenberger. Howell Book House, Inc. 1963.

Carson, Rachel Silent Spring - Houghton Miffin Co. Boston 1962.

There are also books that are of special comfort to the patient, parent or family:

Carlson, Karl R. Born That Way. John Day 1941.

Buck, Pearl The Child That Never Grew. John Day and Co. 1950.

Brown, Christy. My Left Foot. Secker and Warburg. 1954.

Kirk, Samuel A. Karnes, Merle B., Kirk, Winifred D. You and Your Retarded Child. MacMillan 1955.

Lewis, Richard S. Strauss, Alfred A., Lehtinen, Laura E. The Other Child. Grune and Stratton, N.Y. 1960.

Smith, Bert Kruger No Language But A Cry. Beacon Press 1964.