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CATALYSTS FOR CHANGE: PARENTS OF THE HANDICAPPED
1930 - 1960

by
Janis B. Fine

A Dissertation Submitted to the Faculty of the Graduate School
of Loyola University of Chicago in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy

May
1989

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PREFACE

Somewhere, even as you read this, a child is being born with a handicap. It may be deafness, which will make the wonder of a Mozart sonata a life-long mystery. It could be blindness, precluding the child from ever knowing the grandeur of a far-off mountain range. Or it could be cerebral palsy, which will forever deny the child from running through a grassy field or climbing an old oak tree. And somewhere, too, the parent of a handicapped child is being born into an unexpected world of heartache, despair, and shattered dreams.

As a speech pathologist in the Chicago public schools for more than a decade, I have come to know hundreds of parents of handicapped children. Sitting across from them in staffings during which we have teamed to develop goals and objectives to meet their children's special needs, I have often felt I was in the midst of society's unsung heroes. Here were people who had kept their children at home, raised them with all the time and energy which that implies and often without sufficient help from the community, neighborhood, professionals, friends, or relatives--in fact commonly against their well intentioned advice. They have founded parent groups, held fund raising events, and built special

playground equipment. They have attended school board meetings, and have written state legislators about their children's needs and rights. They have successfully merged together in class action suits to bring about the legislation which has mandated the very staffings at which we have been sitting.

It was indeed the parents who had turned around the inadequacies of provisions for the handicapped. But the law mandating free public education for all handicapped children did not come into effect until the late 1970s. I wondered what had taken so long. Why had the parents not banded together sooner? What had kept them from organizing their efforts decades earlier? Why had they stood idly by while society mishandled, mistreated, and often simply neglected their needy children?

My early research revealed that a grass roots movement of parent groups began in the late 1930s. I intended to cover the rise of this movement until its nationwide expansion in the 1950s. Yet further research revealed that there was a bigger story to be told. Before the parents could ever begin to make demands, they had to dispel centuries of myths that had long branded the handicapped as purveyors of evil and menacing taints to society. They had to destroy the long ingrained notion that the parents were to be condemned for defiling our otherwise "pristine society" with less than perfect hereditary or environmental conditions which produced

blemished offspring. It therefore became necessary to return to the primitive societies where the roots of such debauchery began.

Through an historical perspective, it became increasingly clear to me that the handicapped were the victims of the existing attitudes and conditioning factors throughout the ages. It took the turn of the twentieth century with its Progressive Movement to create conditions in society which engendered an environment ripe for the rise of the handicapped parent movement. What began as a few brave whispers in the 1930s crescendoed to a tumultuous roar by the 1950s.

It is hoped that in viewing the battle waged by the parents, the reader will experience outrage and contempt toward the violations of human dignity that prevailed for so long. It is hoped too that the reader will be inspired to continue the humane, socially sensitive attitudes presently promulgated toward the handicapped community.

VITA

The doctoral candidate, Janis B. Fine, is the daughter of Jay and Adelaide Bellows. She was born on 15 May 1953 in Chicago, Illinois.

Mrs. Fine attended Luella Elementary and Bowen High School in Chicago. She received the Bachelor of Science degree in Speech Pathology and Audiology from the University of Illinois in 1975 and the Master of Science degree in Speech Pathology from the University of Illinois in 1976.

In September of 1976 she began her career as a speech pathologist in the Chicago public schools. Mrs. Fine is presently the Lead Speech Pathologist for District 31 High Schools North and the Speech Pathologist at Amundsen, Mather and Senn High Schools in Chicago.

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CHAPTER I

HISTORY OF EXCEPTIONALITY

Wrought into the long existence of mankind are many factors which condition the life of every individual and the purposes and functions of man's institutions.¹

- Edward H. Reisner, Educational Foundations (1937)

Thus a noted educator characterizes the social culture of the ages. These many factors have brought changes during the course of time which have produced either advancement or obstruction in the progress of human history. It is unfortunately so that the effect upon handicapped individuals, more often than not, has been to make them victims rather than beneficiaries of these conditioning factors and attitudes.

The story of the handicapped on the pages of world history is saddening and pathetic. Available documentation reveals that since early times there has been a misconception that the handicapped are subhuman contaminants of the human race. They have been regarded as both product and progenitor of evil heredity and social degeneracy.

In historical perspective it is possible to see the enormous injustice perpetrated upon handicapped persons and their families. The story of the handicapped not only reveals their particular plight, but also reflects the

struggles and conflicts of the parents in their efforts to secure understanding and hope in a too often non-accepting social order.

FOUR DISTINCT HISTORIC PERIODS

Historically, four stages in the development of attitudes toward the handicapped child can be recognized.² These periods are approximately as follows: (1) Primitive Times or prehistoric days. (This period witnessed the "Survival of the Fittest" among handicapped in tribal societies); (2) Ancient Times, dating from about 1300 B.C. to about 476 A.D. (This period may be analyzed principally for its philosophy and social treatment of the handicapped through authentic records and accounts); (3) The Middle Ages, approximately 500-600 A.D. to around 1500 A.D. (This period was dominated by Christian religious thought); and (4) The Modern Period, after 1400-1500 A.D. (This period witnessed the influence of the scientific movement on the attitudes toward the handicapped.)

Primitive Times

In prehistoric days nature herself eliminated the handicapped by the process of the survival of the fittest. As they were incapable of battling nature and equally unable to detect and combat enemies, death came to them swiftly. Then, as tribes developed from small family groups, a formal process of elimination developed. The

handicapped, unable to assume responsibility, delayed the movements of the roving tribe. They composed an economic hazard to the group in that they neither joined the hunt nor assisted in the production of food supplies. They required the safeguard of their tribesmen against both wild beasts and tribal enemies. If they were deserted by the fleeing tribe, the handicapped were easily captured by the enemy and often became the victims of cruel ceremonies and rites.

Ancient Times

The first reference to the deaf appears in Greek history in the fifth century B.C. by Herodotus who mentioned the deaf son of Croesus. While Hippocrates noted that in deafness the lack of speech was due to loss of the use of organs, Aristotle, a century later, stated: "Those born deaf all become speechless." A confusion arose over the meaning of the word "speechless" which in Greek contained the additional meaning of "senseless" or "lacking sensation" and which led to the implications of the word "dumb" meaning speechless. The ancient world apparently followed the couplet of Lucretius: "To instruct the deaf, no art could ever reach. No care improve, and no wisdom teach." It is stated that the Athenians put deaf children to death and that the Spartans condemned them to the great pit in Taygetus.³

In keeping with the ancient Greek's admiration for physical perfection and the Athenians' worship of beauty, infanticide was widely practiced. Physically handicapped children were exposed, destroyed or deserted. Sparta had a law providing for the destruction of the crippled. Such children were thrown into lakes or left in the woods to die. Cripples, dwarfs and other physically deformed persons were otherwise exploited as jesters and entertainers for the courts. Even the Roman Law of the Twelve Tables allowed the parent to decide whether he wished his child to be destroyed.⁴

The mentally handicapped suffered as objects of social mistreatment and neglect. They were considered demon-possessed. Their confused mumblings were taken as manifestations of evil spirits. The laws of Lycurgus permitted abandonment of "idiots."⁵

Among the early Hebrews the Talmud and Midrash mention four handicaps: deafness, dumbness, blindness, and lameness. The law recognized the blind and deaf, and admonished that they were to have special consideration: "Cursed be he that maketh the blind to go astray in the way"⁶ and "Thou shalt not curse the deaf, nor put a stumbling-block before the blind, but thou shalt fear thy God: I am the LORD."⁷

Certain social limitations were, however, placed upon the handicapped. These related to the laws of ceremonial

uncleanliness which excluded defective persons from sacrificial offerings for religious ceremonies. In Leviticus 21:18-21, the Hebrew philosophy is expressed in the following words:

18. For whatsoever man he be that hath a blemish, he shall not approach: the blind man, or a lame, or he that hath a flat nose, or anything superfluous;

19. or a man that is broken-footed or broken-handed, or crook-backed, or a dwarf, or that hath a blemish in his eye, or is scurvy, or scabbed, or hath his bones broken;

20. or crook-backed, or a dwarf, or hath his eye over-spread or is scabbed or scurvy, or hath his stones crushed;

21. no man of the seed of Aaron, the priest, that hath a blemish, shall come nigh to offer the offerings of Jehovah made by fire: he hath a blemish; he shall not come nigh to offer the bread of his God.

The coming of Christ brought forth compassion for the handicapped. Jesus preached a new way of life--one based on love and mercy. His marked concern and sensitivity to children was expressed on a number of occasions. One response to His inquiring disciples has been interpreted as

the "principle of the Least," frequently quoted with regard to those who are mentally retarded:

An argument started among the disciples as to which of them would be the greatest. Jesus, knowing their thoughts took a little child and had him stand beside him. Then he said to them, whoever welcomes this little child in my name welcomes me; and whoever welcomes me welcomes the one who sent me. For he who is least among you all--he is the greatest.⁸

Later in a letter to the Thessalonians, the Apostle Paul wrote, "Now we exhort you, brethren, warn them that are unruly, comfort the feebleminded, be patient toward all men."⁹

Jesus' mission frequently involved the healing of the blind, the deaf, the cripple, the demonic, the epileptic and the paralytic. Such healing was based on faith and the dispelling or exorcism of demonic influences. His teachings and His healings, with their implication of evil spirits and the devil, were to have a tremendous influence on the future course of many attitudes and social development.

The Middle Ages

The Middle Ages reflected a contrast in attitude. To the religious, the handicapped represented souls to be

saved. To nobility, they continued to provide amusement, entertainment, and a source of mockery. It was also in this period that witches were hunted and burned. Anything inexplicable was attributed to black magic. In the case of the handicapped, exorcisms were performed in order to drive the evil spirits out of the victim's soul.

The treatment of the deaf during the middle ages obeyed the feudal law which was based on the code developed under Emperor Justinian in the sixth century.¹⁰ The deaf were not permitted to enjoy fiefs and other feudal privileges. No attempt was made to educate them as they continued to be considered uneducable.

The Middle Ages were characterized by ridicule and scorn for the crippled. The only occupation for a physically handicapped person was that of court jester. Evidence of only one instance of public provision for the crippled was made from the time of the Twelve Tables in Rome to the twelfth century. In 590 A.D., Pope Gregory included the crippled among other unfortunates who were to be provided with public money.¹¹

The Modern Period

A new philosophy emerged in the sixteenth and seventeenth centuries which influenced the attitudes toward the handicapped. Realism, with its emphasis on the use of the senses and the inductive method in education, was a reaction both to Scholasticism, with its reliance on

Aristotelian logic, and to the development of humanistic education with its emptiness of mere words and style. Here was the beginning of the replacement of literary and linguistic studies by material from nature and life. It was the beginning of the scientific approach to education and the study of the child as an individual.

John Locke (1632-1704) and Jean Jacques Rousseau (1712-1778) underscored these views. Locke, in Essay Concerning Human Understanding, ascertained that ideas were formed through inductive processes. His conclusion was that the mind is a "tabula rasa," a passive receptor of knowledge through the senses. This postulate became the basis of sensationalism. Its emphasis on sense perception led to the belief that books should not be the most important source of learning; rather learning should be based on sensory impressions. Rousseau's naturalism was philosophically related to Locke's sensationalism which was also known as empiricism. Education, Rousseau maintained, should be based on the nature of the child, not on the requirements of an artificial society. The original capacities of each child should be allowed unrestricted expression.

It was during the eighteenth century that the first attempt was made to base the training of the handicapped on the development of the senses. Jacob Rodriguez Pereira, a French physician whose sister was a deaf-mute, noted that a

baby who is born deaf often understands speech, and even uses it as long as he lies on the vibrating chest of his mother. Put down to crawl and walk, he is from then on a deaf-mute. Pereira's inspired conclusion was to teach speech by touch and sight. The pupil grasped the master's throat while watching the facial movements that produced the sound vibrations. Pereira urged that the deaf should be taught to see, by lip-reading, and to feel, by tactile vibration, the speech they could not hear.¹² Pereira was considered to be the pioneer in all fields of the handicapped in that he taught "unfortunates the art of thinking." Rousseau is said to have visited Pereira's school and found in it living proof of his theories. In his practice, Pereira endeavored to carry out Rousseau's educational philosophy.¹³

The Modern Period also witnessed the use of the senses toward the teaching of the blind. Rampazetto (1575) in Rome taught with carved wooden letters. Francisco Lucas (1580) in Spain, also carved an alphabet on wooden tablets. In Nuremburg, George Harsdorffer (1651) taught the blind to write with a stylus upon wax-covered tabloids. In Italy, Padre Francisco Lana Terzi (1670) used a kind of cipher code based upon a system of angles, points and dots enclosed in squares and figures, thus hinting at later braille.

Before the close of the eighteenth century the first schools for the blind and deaf had appeared. Nothing, however, had been done for children who were physically or mentally handicapped. Even in the Age of Enlightenment there continued to be repulsion toward the crippled, and a spurning of the mentally sub-normal. Both continued to be considered as an indication of Divine displeasure, a chastisement from above upon the parents whose child was so afflicted. The physically and mentally handicapped child became an object of dislike from parents and neighbors alike, and were often hidden away in shame.

Then, in 1798, Jean-Marc-Gaspard Itard (1775-1838), a French physician, became the first man to bring science to the aid of the mentally retarded. Some hunters in a remote woods in France had come across a naked boy wandering alone, eating acorns and muttering gibberish. Naked, dirty, scarred, and unable to speak, he selected food by smell and appeared impervious to heat and cold. He was brought to Paris where he excited much interest and curiosity. He presented a revolting appearance. "A disgustingly dirty child affected with spasmodic movements and often convulsions who swayed back and forth ceaselessly like certain animals in the menagerie, who bit and scratch those who opposed him, who showed no sort of affection for those who attended him and who was, in short, indifferent to everything and attentive to nothing."¹⁴ He was brought

to the Institution National des Sourds-Muets where Itard sought permission to care for the boy, whom he called Victor.

Although others at the institution felt that Victor was a hopeless idiot, Itard felt that the apparent subnormality was due to the fact that he lacked the usual experiences of civilized man. Itard knew of Locke's thesis that all knowledge was acquired by experience, and for five years he attempted to bombard Victor with stimulation of the senses and intense emotion. In the end, he developed into an affectionate boy who lived like a human being. Although he had no speech, he understood much of what was said to him and could even read a few words.

This was the first scientific attempt at the education of those of limited intelligence. It showed how psychological principles could be applied to the problems of learning. It also showed the need for further research. The objective methods which Itard conceived as necessary for instruction were elaborated upon by his pupil, Edward Seguin (1812-1880).

The formal study of the care and training of the mentally subnormal began with Seguin, called the "Apostle of the Idiot." From Itard's concentration on Sense training, Seguin developed his physiological method. It was based on his belief that there existed a link between sensation and idea, and that education of the senses would

therefore nourish the mind. His method was a systematic training of the senses of sight, hearing, taste and smell, and hand-eye coordination.¹⁵

Seguin's influence was enormous. In 1848 Seguin came to the United States. Here he assisted in establishing the first three institutions for the mentally deficient, those of Massachusetts (The Massachusetts School for Idiotic and Feeble-minded Youth, Boston, 1848), New York (State Institute of Albany, 1851), and Pennsylvania (Pennsylvania Training School for the Feeble-minded Children, Elwyn, 1853).

HUMANITARIAN BEGINNINGS

In 1848, Dr. Samuel Gridley Howe of Boston, excited by the work done in Europe and his own efforts in teaching the blind and the deaf-blind, persuaded the Massachusetts Legislature to appoint him as head of a commission to inquire into the conditions of the mentally subnormal, to determine their number, and whether anything could be done to help them. In his report to the Commonwealth on the condition of its idiots, Howe petitioned on behalf of the continuing reformation of the Massachusetts educational system:

Massachusetts admits the right of all her
citizens to a share in the blessings of

education; she provides it liberally for all her more favored children; if some be blind or deaf, she still continues to furnish them with special instruction at great cost; and will she longer neglect the poor idiot--the most wretched of all who are born to her--those who are usually abandoned by their fellows--who can never, of themselves, step up upon the platform of humanity, will she leave them to their dreadful fate, to a life of brutishness, without an effort on their behalf?¹⁶

In appealing to the humanity and justice of the legislature before him, Howe continued:

It is true, that the plea of ignorance can be made in excuse for the neglect and ill treatment which they have hitherto received; but this plea can avail us no longer. Other countries have shown us that idiots may be trained to habits of industry, cleanliness and self-respect; that the highest of them may be measurably restored to self-control, and that the very lowest of them may be raised up from the slough of animal pollution in which they wallow; and can men of other countries do more than we?

The benefits to be derived from the establishment of a school for this class of persons, upon humane and scientific principles, would be very great. . . . It would be demonstrated that no idiot need be confined or restrained by force; that the young can be trained to industry, order and self-respect; that they can be redeemed from odious and filthy habits, and that there is not one of any age who may not be made more of a man and less of a brute, by patience and kindness, directed by energy and skill.¹⁷

Howe then undertook the first systematic survey of a mentally defective population. Finding 755 "idiots" in 182 towns with a combined population of 392,586, Howe concluded that on the same ratio of two per thousand, there was a total of 33,000 in the U.S. Of those whom he identified, Howe concluded that of the 200 under age 25, 196 could be helped.¹⁸

The legislature appropriated \$2,500 annually for three years to educate ten idiots. Thus, the first public residential institution in the United States was established as the Massachusetts School for Idiotic Children and Youth. Joined by Seguin, whom Howe had met in Paris and who came to the U.S. during the revolution of

1848, and Dr. Harvey B. Wilbur who had begun a small private school in Boston, Howe went on to establish state schools in New York (1851) and Pennsylvania (1853).

From the start, Howe, Seguin and Wilbur demanded that the schools be organized "upon the plan of a family, with a kind of mother person in care." Of the improvements of the idiots, Howe wrote, "It is hoped that part of them will gain some really useful knowledge; that most of them will become cleanly decent, temperate and industrious; and that all of them will be better and happier from the efforts made in their behalf."¹⁹

In 1851 Wilbur, in Albany, opening New York State's first institution, stressed in the bylaws of that organization the pursuit of the educational goals of the school:

The design and object of the asylum . . .
are not of a custodial character but are to
furnish the means of education to that
portion of the youth of the state not pro-
vided for in any of its other educational
institutions.²⁰

In 1852 Howe reasserted firmly in a report to the Massachusetts House of Representatives:

This establishment is called a school, and
it is a link in the chain of common
schools, the last indeed, but still a
necessary link in order to make the chain

embrace all the children in the state.
. . . All are to be kept busy, and render work, if it be but doing chores about a house or farm . . . if they be properly taught and trained to industry, a few of them will contribute something towards their own support and almost all of them will become less burdensome and expensive.²¹

In an 1854 Report of the New York Asylum for Idiots, Wilbur noted that its sole concern be with the education during the "best learning years" and that those in residence then be "returned to their families." However, two years later (1856), Howe reported that:

There is the greatest reluctance on the part of the parents and guardians to remove those pupils whose terms have expired . . . because they think they are better here. This is especially true of the most unfortunate children--of the lowest idiots.²²

Howe continued to extol praise upon the achievements of the institution in a letter to the Governor of Massachusetts:

True it has not changed the nature of any born idiot and given him common sense, and no honest and wise person have pretended this could be done. But . . . it has shown that idiots form no exception to the law

that every form of organized life is capable of being changed for better or worse by surrounding influences. . . . It has rescued some children of merely feeble minds from the imbecility into which they had fallen . . . many trained to habits of industry.²³

But in the same letter to the Governor, Howe entered into a theme in which he would become increasingly absorbed until his retirement in 1874, the dangers of institutions:

In almost all public, charitable and penal institutions with which I am familiar, serious evils arise from violation of the principle that we should separate not congregate. . . . Being called upon lately to give advice about the establishment of institutions for the Blind and Deaf Mutes in a new State, I have counselled a course different from the one I, myself, followed many years ago. It is to dispense with any great costly building, having common dormitories, dining rooms, chapel and the like. To make no great preparations for any great common household at all; but to build a simple building, with all the conveniences for conducting classes, and

make provisions for boarding the pupils in private families. In a word to reduce the Institution . . . to its simplest form. This is perfectly feasible in many small towns and villages.²⁴

Almost ten years later, with the rapidly expanding development of institutions, Howe spoke vehemently about the inherent evils of the institution:

Society, moved by pity for some special form of suffering, hastens to build up establishments which sometimes increase the very evil which it wished to lessen. . . . Our people have rather a passion for public institutions, and when their attention is attracted to any suffering class, they make haste to organize one for its benefit.²⁵

By 1874 the public institutions were moving rapidly to a dual function of training and custody, with no voice speaking anywhere for meeting the needs of the institutionalized within the community. With a total of six state, one municipal, and two private institutions housing a sum of 1,282 residents, Howe continued to be the sole voice in decrying the persisting dangers. In his retirement report to the Trustees of the Massachusetts School for Idiotic Children in 1874, he claimed:

Now the danger of misdirection in this pious and benevolent work is, that two false principles may be incorporated with the projected institutions which will be rotten piles in the foundation and make the future establishments deplorably defective and mischievous. These are, first, close congregation, and second, the life-long association of a large number of idiots; whereas, the true, sound principles are: separation of idiots from each other, and then diffusion among the normal population.

. . . For these and other reasons it is unwise to organize establishments for teaching and training idiotic children, upon such principles as will tend to make them become asylums for life. . . . Even idiots have rights which should be carefully considered!²⁶

The chief spokesman for institutional life-time custodial care was Dr. I. N. Kerlin, Superintendent of the Pennsylvania Training School for the Feeble-Minded Children (Elwyn). In his annual report of 1875, Kerlin renounced Howe's principle of diffusing the idiotic throughout the community on the grounds that they are really "aliens in their own homes, because they are unlike any other child or

member of the family; foreign to the community, because subordinate to its rules and habits; children always even when men in stature, of necessity they come to be repelled from home and society."²⁷

Howe's impassioned pleas continued to fall on deaf ears. With his retirement ended the consideration of the rights of the impaired. The next several decades would witness the dehumanization of individuals who were impaired, and their emerging image as being dangerous and threatening to social decency.

CAMPAIGN OF CONTROL

The occasion of the Centennial Exposition at Philadelphia in 1876, bringing together people of all classes, from all parts of our country, seemed to make it feasible for the first time to call an assemblage of representatives of institutions devoted to the care and education of idiotic and feeble-minded children; accordingly, the management of the Pennsylvania Training School issued an invitation to all other existing institutions in the United States to meet at Media, Pennsylvania.²⁸

Thus began, one year after Howe's death, the first meeting of the American Association of Superintendents of

state Schools for the Feeble-minded, the forerunner of the American Association on Mental Deficiency.

On motion of Dr. Kerlin, an election of officers for 1876-77 was held under the adopted Constitution, resulting in Seguin as president, Wilbur as vice-president, and Kerlin as secretary. These officers, along with those in attendance, developed the Constitution of the association. Article II of the Constitution established the purpose of the association:

The object of the Association shall be the discussion of all questions relating to the causes, conditions, and statistics of idiocy, and to the management, training, and education of idiots and feeble-minded persons; it will also lend its influence to the establishment and fostering of institutions for this purpose.²⁹

And lend its influence it did! The next several years saw the association and its members enacting deliberate programs to identify, segregate, and sterilize every feeble-minded person as a menace to social decency and racial purity. Contributing to the association's emerging ideology of social control were two concurrent scientific developments which became popularized in distorted form: Social Darwinism and Mendelian genetics.

Social Darwinism

Social Darwinism was derived from Charles Darwin's theory of evolution which was based upon natural selection. Published in 1859, Darwin's On the Origin of Species postulated the principle that individuals possessing characteristics advantageous for survival in a specific environment, constitute an increasing proportion of their species in that environment with each succeeding generation.³⁰

Darwin's theory of natural selection (Survival of the Fittest) was adapted to the social sciences by Herbert Spencer (1820-1903), the foremost spokesman of the Social Darwinist ideology.³¹ Conditions for survival in industrial society had put a high premium on intellectual traits for those who had upward mobility. Intelligence of a high order was essential for scientific and technological development. Low levels of intelligence came to epitomize inability to actively compete for the good things in life. Members of the association grabbed on to the tenets of Social Darwinism, and would come to view limitations of intelligence as stigmatic and degrading to a complex social order.

Mendelian Genetics

Another outside discipline, biology, was exerting its influence on the social sciences. Research interest in heredity was based on the genetic studies of Gregor Johann

Mendel (1822-1884), the founder of the science of genetics. While Mendel's study was based on the inheritance of the sweet pea, Francis Galton, in 1869, claimed that Mendel's laws of the principles of heredity were applicable to humans, and that mental ability as well as physical characteristics were transmitted to offspring.³² This was the springboard for R. L. Dugdale, a prison inspector, who traced the descendants of five mentally defective sisters named Juke. Of the seven hundred he discovered, he found that over four hundred of them were criminals, prostitutes or paupers.³³ This was a sociological description of the frequency of social degeneracy in blood relations. It was, however, seized upon by the association as proof of the hereditary nature of degenerative tendencies.

By 1891 in an effort to identify the causes of idiocy, the following was read at a meeting of the American Association of Superintendents of the State Schools for the Feeble-minded:

The most frequent cause of idiocy is, no doubt, ill-assorted marriages; marriages of persons of the same morbid tendencies. A tendency to consumption furnishes the largest number of cases. Intemperance of parents is another cause. . . . In twenty-five percent of idiocy there is antecedent maternal anxiety and over-tax sufficient to

enter as a direct or accessory cause of the infirmity; fifty-six percent of idiocy descends from scrofulous and consumptive families; in thirty-four percent there is a family history of alcoholism, with cases of epilepsy, nervous disease, and crime in the same inheritance; while in twenty-seven percent of cases we find insanity and imbecility begetting idiocy.³⁴

At the same meeting, the classification of idiots was discussed at great length. Kerlin's classifications emerged as the most popularly used. They included "idiots, both apathetic and excitable, idio-imbeciles, imbeciles of lower, middle and upper grades, and moral imbeciles." The consensus of those at the meeting was that the term, "feeble-minded," which was used to refer to those children "often found in the public school, with little advantage to themselves and great detriment to the schools" was the most appropriate for generic use.

It was at the conclusion of that meeting, however, that the groundwork was firmly laid for the image of the feeble-minded as a depraved menace to society. In formulating some of the reasons that the state should care for its feeble-minded, the following causes and explanations ensued:

1. The State should systematically care for and train its feeble-minded for the same reason that it educates its deaf and blind youth. . . . It is hard to conceive a reason for the public care of other defective classes which does not apply with equal or greater force to these poorest of nature's step-children.

2. The State should nurture its feeble-minded for the same reasons which demand the care of its insane. . . . Does the public safety and comfort require the sequestration of the insane? The same is true, in scarcely less degree, of the feeble-minded. To protect society against all causes of injury, alarm, or offense against decency is a proper public function in the one case as in the other. And the relief of the home from the terrible burden which idiocy entails comes clearly within the field of public charity and public policy.

3. The State should hasten to care for its feeble-minded as a measure of social self-preservation for the greater health, physical and moral, of the body social.

. . . How many of your criminals, inebriates, and prostitutes are congenital imbeciles? How many of your insane are really feeble-minded or imbecile persons, wayward and neglected in their early training, and at last conveniently housed in hospitals, after having wrought mischief, entered social relations, reproduced their kind, defied laws, antagonized experts and lawyers, puzzled philanthropists, and in every possible manner retaliated on their progenitors for their origin and on the community for their misapprehension? How many of your incorrigible boys, lodged in the house of refuge to be half-educated in letters and wholly unreached in morals, are sent out into the community the moral idiots they were at the beginning, only more powerfully armed for mischief? And pauperism breeding other paupers, what is it but imbecility let free to do its mischief? . . . Can such alarming facts be wisely met by the neglect of idiots or by leaving them under the conditions ordinarily found in poor-houses? Is there any safety in anything less than a haven for

imbecility where they shall go no more out
and there shall be neither marrying nor
giving in marriage?³⁵

Negative Eugenics

Thus was launched the negative eugenics movement based on Social Darwinism. By applying the Darwinian theory to the human race, it would be possible to eliminate the unfit, and man could actively assist nature in promoting the survival of the highest quality of human being. This was what Martin W. Barr, President of the Association of Medical Officers of American Institutions for Idiotic and Feeble-Minded Persons, proposed in his presidential address in 1897:

With imbecility and its many phases of sexual perversion, recognized as a disease --a sure means of transmitting inherited taint--it does seem absurd that while we wage war upon microbes and bacilli, we turn loose this worse than leprosy to poison the very springs of life. . . . All seeds, all buds, do but perpetuate their kind, and we but follow the lesson taught when we shake the bough from which falls defective fruit. We choose and set apart with care the animals best fitted for procreation, and by castration render more docile, because less

passionate, the beasts of burden who are to mingle in the common herd. They rove at will free and unrestrained--because harmless. I need not point the moral nor draw further analogy.³⁶

Now the "true" implications of the Jukes family became clear. Other family histories were rapidly brought forth as further appalling examples. The most famous was the story of the Kallikak family by H. H. Goddard (1882-1945). This study was taken as absolute proof of the genetic origin of feeble-mindedness. It traced the lineage of an eight year-old mentally deficient girl, Deborah Kallikak. It revealed that her great-great-great grandfather, Martin, Sr., had a misguided adventure with a feeble-minded girl whom he met in one of the local drinking establishments. That relationship resulted in the birth of an illegitimate son, Martin Kallikak, Jr., from whom came 408 direct descendants. One hundred forty-three of these were feeble-minded according to Goddard who said he had "conclusive proof were feeble-minded"; thirty-six were illegitimate; thirty-three were sexually immoral persons, mostly prostitutes; twenty-four were confirmed alcoholics; eighty-two died in infancy; three were epileptic; three were criminals; and eight kept houses of ill fame. Only forty-six were found to be "normal."

Later, Martin Kallikak, Sr., who was of normal intelligence and from a "good" family, married a woman with equal credentials, and from this union descended in direct line 496 people, none of whom was mentally defective and only one insane. Only three, according to Goddard, were in any sense degenerate, two being alcoholics and one sexually immoral. Thus, Goddard concluded:

The Kallikak family presents a natural experiment in heredity. A young man of good family becomes through two different women the ancestor of two lines of descendants--the one characterized by thoroughly good, respectable, normal citizenship, with almost no exception; the other being equally characterized by mental defect in every generation. This defect was transmitted through the father in the first generation. In later generations more defect was brought in from other families through marriage. In the last generation it was transmitted through the mother, so that we have here all combinations of transmission, which again proves the truly hereditary character of the defect.³⁷

Public interest was challenged by the subject as never before. It was outwardly hostile and repressive. The

expression of opinion became that we must corral these people that threaten the very continuance of our civilization; we must adopt methods to stop the alleged disproportionately higher rate of reproduction of their type; we must build more and bigger institutions in which to confine them; we must remove from them the physical capacity of reproduction.

Sterilization of the unfit became a popular subject. While Martin Barr had talked of this back in the 1890s, here in the second decade of the 1900s the general public had at hand brilliant examples of the results of breeding-up; flowers, plants, dairy cows: why not apply these principles of positive eugenics to prevent the creation of feeble-minded human stock?

In 1913, just one year after the publication of The Kallikaks, the Eugenics section of the American Breeder's Association, at its annual meeting, appointed a committee of its members to study and report upon "practical methods of eliminating defective germ plasm from the human population." The committee, meeting in 1914, reported the problem as such:

In recent years society has become aroused to the fact that the number of individuals with its defective classes has rapidly increased both absolutely and in proportion to the entire population; that some normal

strains are becoming contaminated with anti-social and defective traits. . . . Within the last three years especially there has been a marked development of public interest in this matter. The word "eugenics" has for the first time become known to thousands of intelligent people who now seek to understand its full significance and application.³⁸

The campaign of control became most blatantly evident as the Eugenics section proposed that the following classes must be considered:

as socially unfit and their supply should if possible be eliminated from the human stock if we maintain or raise the level of quality essential to the progress of the nation and our race: the feeble-minded, the pauper class, the criminaloids, epileptics, the insane, the constitutionally weak, those predisposed to specific diseases or the diathetic class, the congenitally deformed, and those having defective sense organs, such as the deaf-mutes, and the deaf and blind.³⁹

The second decade of the 1900s witnessed the emergence of sterilization laws in the United States, as well as a

burgeoning of state institutions. The popular consensus of the time was that the state must take control of the defective child away from the parent, who was viewed as causative to the problem, both genetically and environmentally. In The Burden of Feeble-Mindedness, Walter Fernald, long-time associate of H. H. Goddard, addressed the Massachusetts Medical Society:

At the proper time the parents should be informed of the condition of the child, of the necessity for life-long supervision and of the probable need of institution treatment. Sooner or later the parents will probably be willing to allow their child to be cared for in the institution. The parents who are not willing should be allowed the custody of their child, with the understanding that he shall be properly cared and provided for during his life, that he shall not be allowed to get into mischief, and that he shall be prevented from parenthood. Whenever the parents are unwilling or incapable of performing these duties, the law should provide that the child shall be forcibly placed in an institution, or otherwise legally supervised.⁴⁰

Taking control away from the parents was further stressed when Fernald questioned whether parents should be able to take their children out on parole. "We want to keep a legal hold on them and give them a bit of supervision. We either have the choice of doing that or allowing them to be discharged and losing control."⁴¹

The need of the parent was to ensure the security of the handicapped child. With community resources not yet in existence, the institution was the only resource available for the child. Massive attack on the problem was necessary in order to bring about a significant change. The parents would need to organize to dispel the deeply indoctrinated images which made a handicapped child a purveyor of evil and degeneracy. With the Progressive Movement (1900-1930) conditions would develop which would make the time ripe for the rise of the parent movement.

CHAPTER ONE NOTES

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CHAPTER II

PROGRESSIVE MOVEMENT - IMPETUS FOR PARENTS OF THE HANDICAPPED

In considering who changes society, some have divided the world into three groups. There are those who can tolerate the everyday stresses and strains of life; they say little, and these are the average people. There are those who cannot tolerate the everyday stresses and strains of life; and they shout, and these are our leaders. Then, there are those who cannot tolerate the stresses and strains of life; and they whisper and these are our victims. Society has generally demanded that families of disabled children whisper.¹

- Maxwell J. Schleifer, Exceptional Parent (June 1981)

Since ancient times society has blamed and punished those parents who had attempted to shout about their pain and anguish. And finally with the close of the nineteenth century, it seemed parents would unwittingly accept society's limited investment in them. Yet, with the turn of the century, a movement was about to sweep the country which would have a profound impact on social, political, economic and educational developments. Called the Progressive Movement, this era reflected the national mood of reform by the expression of its various trends. The parents of handicapped children seized upon these trends, and found in them the foundations of strength and impetus for their own

movement. Their whispers at the turn of the century were to become, by 1940, a powerful voice, and by 1950 would explode nationally into a tumultuous roar.

In historical perspective it is possible to examine the developments of the Progressive Movement and to view their subsequent influence on the rise of the parents of the handicapped group movement.

NATIONAL CONGRESS OF MOTHERS (PTA)

In 1896 Mrs. Alice McLillan Birney conceived of a Congress of Mothers. This had as its objective the study of the care and training of children and was the first official recognition on the part of parents that parenthood was a profession necessitating study and training. In 1897 Mrs. Birney's idea became a fact, and the National Congress of Mothers was organized with Mrs. Birney as its first president.²

It was 17 February 1897, a day in the Gay Nineties. The business world was enjoying a grand and glorious feeling. Times were booming; fortunes were being made. America was growing daily in strength and wealth. Railroads were spanning the continent, and factories were expanding. Millions of immigrants were pouring in from Europe to swell the reserve of cheap labor.

It was, however, America at the close of an era. The industrial revolution, for all its benefits in increasing wealth and productivity through free enterprise and

technological development, nevertheless produced social side effects of appalling magnitude. The muckrakers, Upton Sinclair, Ida Tarbell and others aroused America to humiliation over the way big fortunes were being made and the way corrupt politics and business were exploiting the public.³

Yet it was neither to exalt the booming times nor to expose disgraces of politics and business that thousands came thronging to Washington in 1897. The crowds of mothers, teachers, and some fathers came with a more comprehensive motive. There were women among them who had seen the misuse of children in factories:

No social standards applicable to the factory system existed to safeguard working children. They were brought into the factory at a very early age, required to work almost unlimited hours and sometimes made to sleep as well as work at the factory. . . . Dependent children lived frequently in almshouses under conditions usually depressing and often degrading and were sometimes apprenticed in gangs to the factory owner, with no further thought to their protection.

The method called "baby farming" by which large numbers of children were boarded with a careless custodian, resulted in a tragically high death rate.⁴

Many of the thousands of mothers who came to Washington in 1897 brought with them somber thoughts about children trapped in their own helplessness. In an interview with the press, a woman from Des Moines decried Iowa's "miserable system of taking care of little folks who roamed the streets for lack of playground space and who broke the law and became child delinquents:

The only place for the detention of these young people is one small room, the most of which is cut up into pigeon holes just large enough for a cot and a chair. . . . It is claimed that the children are kept in the station without any chance for free, fresh air in the summertime, and that boys of eighteen, bordering on incorrigibility, are kept in the same room with little girls. A systematic effort will be made to have the local authorities report to the mothers' clubs every case of incorrigibility coming before them.⁵

In her welcoming address to the National Congress of Mothers, Mrs. Birney echoed what was on the minds and in the hearts of the thousands who descended upon Washington with a sense of social reform. She would speak before a crowd who felt responsible for remedying the ugly aspects of their society. It was the same crowd whose leaders demanded

suffrage, universal peace, abolition of child labor, and prohibition of drinking. Mrs. Birney spoke to those who felt uneasy about the changes which affected their children's welfare:

Gentlemen and Ladies: In coming before you as the President of the First National Congress of Mothers, it is my pleasure and privilege to extend to each and all of you a heartfelt welcome, and to express the hope that this large and gratifying audience, this more than encouraging response to our universal call, may prove in earnest of the success destined to crown the work to which our best and highest efforts are now consecrated. What is the Mothers' Congress? What are its aims and objects? The age in which we live is one of "movements"--it is a time of specialized work and organized effort. It has therefore seemed to us good and fitting that the highest and holiest of all missions--motherhood--the family interest upon which rests the entire superstructure of human life--and the element which may indeed be designated as the foundation of the entire social fabric, should now be the subject of our reverent consideration. I refer to what

is called child study--that broad, deep theme, most worthy, in all its varying phases, of our study and attention.⁶

Child Study and Parent Education

Child study had its beginnings with the work of G. Stanley Hall (1844-1924), psychologist and president of Clark University. He was the first to institutionalize the study of children with the universities, and he more than anyone popularized the idea that the study of children would revolutionize the pedagogy of home and school.

Hall believed in bringing educational practices in line with children's "natural" needs. In so doing, he created a climate for assessing individual differences in children. Just what those natural needs were, could in part be ascertained by a parent questionnaire. Participation in Hall's research forced parents to systematically observe the behavior of their children. Parents thus gained the satisfaction of learning more about their children.

Throughout the first few decades of the 1900s, the PTA strongly advocated the study of children by the parents, known as parent education. In fact, on a weekly basis, local chapters of the PTA would break into small study groups to discuss recent literature they had read beforehand and real and hypothetical problems of child care and management. The National Congress of Mothers Magazine, created in 1906, added further structure to the study groups. Suggested topics came

under broad areas of interest. "Moral Training," "Provisions for the Helpless and Defective," "Treatment of Erring Children," and "Legislations" were just a few of the "suggested topics" appearing in a 1907 issue of the magazine.⁷ Also, the dedication to parent education was strongly stated in a presidential address to the National Congress of Mothers in 1906:

We are fully aware that many organizations are already in existence, and that they are accomplishing great results along these lines, but there is no National movement with the one avowed aim of concentrating the thought of the Nation upon the importance of educating the mothers and, through them the race. We hope to make the Republic realize that its greatest work is to save the children, and this we can accomplish just as soon as mothers' and fathers' hearts are awakened to all the needs of childhood.⁸

Membership in the PTA expanded enormously: from 60,000 in 1915, to 190,000 in 1920, to 875,000 in 1925, to nearly 1,500,000 by 1930. Despite its rapid growth and its formal identification with the subject, the PTA seemed to move away from its preoccupation with parent education, and toward an orientation of providing recreational and entertainment activities for parents. By 1930 the incidence of topic

selection involving handicapped children had dropped from its high priority in 1906. It ranked between Leisure and Art in frequency of occurrence as a topic addressed by the president of the congress. The pre-war interest in parent education as a stepping stone to other social reforms seemed to practically disappear.⁹

By the mid-1920s, the Child Study Association of America (CSAA) was started as a group of German-Jewish women centered around New York's Ethical Culture Society. Led by Sidonie Gruenberg and her husband Benjamin, the CSAA provided post-war parent education. In 1925 it initiated the National Council of Parent Education to coordinate the many lay and professional groups in the field. It sponsored the first university course in parent education at Teachers College, Columbia in 1925. It organized the premiere conference on parent education in the period; this culminated in the influential publication, Concerning Parents. Printed five times between 1926 and 1929, Concerning Parents set new standards for instruction in sex education and pioneered the use of psychoanalysis and mass media as tools of formal adult education.¹⁰

In addition to the PTA and the CSAA, The American Home Economics Association and the American Association of University Women (AAUW) were only two of the lay organizations which included programs in parent education in the 1920s.

PSYCHOMETRICS

In 1905 two French Psychologists, Alfred Binet (1857-1911) and Theodore Simon (1873-1961) developed a technique for distinguishing among children in the schools of Paris those who could succeed in standard school work and those who could not. The Binet Test, based on a sampling of verbal and intellectual performance characteristics of children in successive areas, developed an age-scale by which the degree of retardation or advancement could be measured against a norm. Thus, the science of psychometrics was born.

Binet would have been horrified at the uses to which it was put in the United States. It was seized upon and popularized by Dr. H. H. Goddard, Director of Research at the Training School at Vineland, New Jersey, and by Kuhlman, Terman, and others who refined, perfected, and applied this new and powerful instrument. The efforts of Binet and Simon had not attracted much attention in France. In America, however, their reception under the impetus from Goddard was instantaneous and grew unbounded. Here was something concrete, mathematically exact, prognostic in nature, and something that would not require the long time observation experience of the skilled clinician.

How easily the proclamation of this new discipline was received shows in the following editorial from the Journal of Psychoasthenics in 1910:

The action of the association (American Association for the Study of the Feeble-Minded) on the report of the committee (on classification) illustrates the natural and logical blending of medical and psychological influences in the treatment of the subject of mental defect. In considering this classification, it is well to bear in mind the three phases which the subject presents, viz: 1st, the nomenclature itself; 2nd, the adoption of a psychological basis for grouping cases, and 3rd, the special psychological test used for determining the classification. . . . As to the matter of emphasizing a psychological basis for classification rather than a pathological one, we can see no serious objection to it; thereby we can secure a means of determining quickly even an approximate estimate of the child's mental ability by some system that is of general application and that presents to all, the physician, the teacher, the parent

and student alike, the same mental picture to be referred to a common mental standard.¹¹

Whatever enthusiasm the parents may have felt with this new agent that was able to furnish a more accurate diagnosis, and hence a more helpful treatment, would quickly disappear. In 1913 Goddard read a paper at the meeting of the association entitled, "The Improvability of Feeble-minded Children":

From the conclusion that we have so far drawn, it is evident that our educational treatment must be largely modified. When once we have discovered that a child is stopped in his development it is, of course, useless to attempt to teach him to do anything which requires an intelligence above that which he possesses. It is pretty certain that intelligence develops, as we may say, of itself, and yet we only utilize and exercise what is there, and do not create anything new by any of our training methods. Here, we may conclude that as a rule, feeble-minded children are trainable but not improvable in intellectual capacity.¹²

Originally yielding a measure of "mental age," Goddard was able to reclassify deficient persons in terms of the maximum mental age attained: the idiot not more than a two year mentality; the imbecile between two and four years; and

the moron seven to twelve years. Stern and Terman--by taking the ratio of mental age to chronological age, with sixteen as a constant at intellectual maturity--invented the intelligence quotient, or "I.Q." The infallibility of the Binet Test, psychometric method, mental age, and of the I.Q. would all be a fetish to be revered and protected from all doubt and attack, particularly in the educational field.¹³

It took over a decade before the American Psychiatric Association in 1926 cautioned about the uses of the psychometric tests:

Psychometric tests, like other laboratory tests, are to be used only when indicated, and then after the completion of the clinical history and examination. There seems to be, at present, a hysteria of intelligence testing rampant throughout this country. One important point in the use of psychometric tests is the necessity for leaving them to the psychologist to do and insisting on the fact that you are interested only secondarily in the field scores obtained and that the most important point is, how did the patient get the scores and what were his reactions throughout the test to various situations and the different questions.¹⁴

Finally in 1929, Goddard restated his positions in remarks before the American Association on Mental Deficiency:

We now know that only a small percentage of the people who test twelve are actually feeble-minded--that is, are incapable of managing their affairs with ordinary prudence, or of competing in the struggle for existence. Even those of eight year intelligence are not all feeble-minded according to the definition.¹⁵

By 1941, almost 30 years after Goddard's statement that the feeble-minded were trainable but not improvable, a well-known child psychiatrist passionately announced:

Already the humanization of the feeble-minded is making progress. Already a number of competent research workers are beginning to break down the notion of the homogeneity of the feeble-minded by discovering hitherto unobserved group differences among them. Already, many of the spastics, believed to be hopelessly inadequate until a short while ago, have been lifted out of the human waste basket and given a new lease on life and hope. Already psychologists and psychiatrists are ceasing to set themselves up as diagnostic and prognostic judges, to treat

the word mental deficiency as a swear word and to use the I.Q. for the purpose of modified horoscope readings. Already word has gotten out that the I.Q. itself is not always immutable.¹⁶

In the meantime, what had happened in public education to children who were handicapped? Were they being cared for? Were they being educated?

PUBLIC EDUCATION FOR THE HANDICAPPED

Before the turn of the century, public education was having its difficulties, especially as the social problems of the cities grew with the expanded population. The rise of compulsory education, which was designed in part to keep children off the streets with the passage of child-labor laws, added to the difficulties. Discipline became difficult, and "problem children" multiplied. The first special classes established in public school in the United States for children with special needs were for unruly, disciplinary, or truant boys, such classes having been started in New York City in 1874 and in Cleveland in 1875. Providence, Rhode Island has been credited with establishing the first "school for backward children" in 1896. It was an offshoot of a "school for special discipline and instruction" for behavioral cases that was opened in the spring of 1894. In reality, however, it became a place to send the "mental

deficients." There followed in rapid succession the establishment of special classes for the blind (Chicago 1896), orthopedically handicapped (Chicago 1899), speech defectives (New York 1908), epileptics (Baltimore 1909), partially sighted (Roxbury, Massachusetts 1920), and the hard of hearing (Lynn, Massachusetts 1920).¹⁷

Within the next decade dozens of cities followed suit, with some establishing two types of special class: one for intellectually limited; and the other for the emotionally or behaviorally maladjusted. In most cases, however, there was a mix of the two and many of them became nothing more than dumping grounds for children whose teachers found them for any reason difficult to handle in any way. Very often, the teachers of these special classes and schools were qualified more as disciplinarians than as special educators. At the same time, and especially in smaller communities, slow learning and retarded children were frequently retained in regular classrooms, learning little, but being tolerated so long as they were docile.

By 1922, 133 cities in twenty-three states were reported by the U.S. Office of Education to have enrollments of 23,252 pupils in special education classes of all types. By 1936 this had increased to 99,621 pupils in 643 cities in forty-three states. State laws providing for special education of retarded children began with New Jersey in 1911 and extended to fourteen states by 1930.

The state laws varied widely. Most of them initially made provisions for special classes only on a permissive basis and without special subsidy. Some states financed excess costs in one form or another; some did not. Some provided teacher training and state supervision; others did not. Practices within cities and from school to school were extremely diverse. The proportion of students, as well as the reasons for placement, varied widely.¹⁸

The one characteristic that was nearly universal to 1940 was the right of the school to exclude a child who was judged "ineducable." This meant incapable of making discernible progress in the formal academic curriculum. Of all the precipitating conditions, this was to become the most compelling toward the rise of the parent group movement.

FEDERAL PROGRAMS

Progress in the twentieth century toward the treatment and consideration of the handicapped was slow. Without the entry of the federal government, progress would have remained meager, slow, and uneven. Legislative landmarks and White House Conferences addressed the conditions of the handicapped.

Legislative Landmarks

Major legislative landmarks leading to federal recognition of the handicapped began with the establishment of the Office of Education in 1867. Early in the 1920s a section

on Exceptional Children and Youth was developed which documented activities in the education of handicapped children.

In 1912 the Children's Bureau was established as a constituent agency of the Department of Labor. The Children's Bureau was the first agency to look at the plight of handicapped children. Following that, in 1935 the Social Security Act gave the Children's Bureau additional funds and responsibility for crippled children and child welfare.

White House Conferences

Called by President Theodore Roosevelt, the Conference on the Care of Dependent Children (1909) brought together representatives of charitable organizations, children's aid societies and others concerned with social welfare. The theme of the conference was that "Home life is the highest and finest product of civilization" and that "children should not be deprived of it except for urgent and compelling reasons."¹⁹

The Children's Bureau Conference in 1919 was called by President Wilson. The theme of the conference was the necessity for more public effort in behalf of children, and the expenditure of that effort in light of the individual characteristics of the child. One of the special committees was concerned with Protective Standards for Children with Special Needs.

Called by President Hoover, the 1930 White House Conference on Child Health and Protection was most notable for its comprehensive concern for mentally and physically handicapped children. Brought to light at the conference were the despicable practices in the treatment of the handicapped. There was persistent evidence that deficient persons were found in higher proportions in penal and correction institutions, but at the conference it was attributed more to their poor social environment than antisocial tendencies.

The White House Conference on Children in a Democracy in 1940 had as its main thrust the development of adequate child welfare services at local and county levels as an adjunct to general welfare services in the community. Part of the report of this Conference was a discussion of the result that the depression years had on the institutions. They had become so crowded and their facilities so meager that they could do little training or treatment. Thousands of handicapped children on the waiting lists of institutions were without other needed social services. Recommendations of this Conference included: (1) modified school curricula in regular or special classes appropriate to learning capacity, under a statewide plan; (2) sufficient availability of institutional care to those requiring it; and (3) early discovery and diagnosis with assistance to parents in understanding the problems faced by their children.

The growth and march of the handicapped parent movement can be likened to a volcanic eruption. For a long, long time there were underground mutterings and rumblings mostly under the surface of society. Yet, by the 1930s, following three decades of progressive reform, the sparks and stones would begin to erupt. Backed by parent education and child study movements which demanded that the parents help their children, and federal programs that provided assistance and mandated reforms, the parents had the impetus of the Progressive Movement behind them. Most of the inequities and injustices toward the handicapped still prevailed. Myths would die slowly and prejudicial images would persist. The parents of the handicapped were to have a tedious march forward; but it was to be a march of growing numbers and rising voices.

CHAPTER TWO NOTES

¹ Maxwell J. Schleifer, "Let's All Stop Blaming the Parents," Exceptional Parent 11, no. 3 (1981): 16.

² The National Congress of Mothers changed its name in 1908 to the National Congress of Mothers and Parent-Teacher Associations. In 1924 the name was changed again to the National Congress of Parents and Teachers.

³ Upton Sinclair, The Jungle (Cambridge, Massachusetts: Robert Bettley, Pub., 1906), revealed the unsanitary conditions in the Chicago meatpacking industry. Ida Tarbell, The History of the Standard Oil Company (New York: The Macmillan Co., 1904), exposed the power and practices of great corporations and strengthened the movement for outlawing monopolies in the U.S.

⁴ E. Seligman, "Child Welfare," in Encyclopedia of Social Sciences, 1932 ed.

⁵ National Congress of Parents and Teachers, Through the Years (Washington, D.C.: National Congress of Parents and Teachers, 1920), 6-8.

⁶ National Congress of Parents and Teachers, Twenty Years Work for Child Welfare 1897-1917, (Washington, D.C.: National Congress of Parents and Teachers, 1920), 6-8.

⁷ "Suggested Topics," National Congress of Mothers Magazine 2, no. 2 (1907): 37.

⁸ Mrs. Frederic Schoff, "Message From the President of the Congress," National Congress of Mothers Magazine 1, no. 1 (1906): 1.

⁹ "President's Reports," Proceedings of National Congress of Parents and Teachers 1929-1931 (Washington, D.C., 1931).

¹⁰ Child Study Association of America, Concerning Parents (New York: New Republic, 1926, 1929).

¹¹ "Editorial," Journal of Psycho-Asthenics 15 (1910): 68.

¹² H. H. Goddard, "The Improvability of Feeble-Minded Children," Journal of Psycho-Asthenics 17, (1913): 121.

¹³ W. Stern, The Psychological Methods of Testing Intelligence (New York: Warwick, 1904).

L. M. Terman, The Measurement of Intelligence (New York: Houghton Mifflin, 1916).

¹⁴ H. W. Potter, "Mental Deficiency and the Psychiatrist," American Journal of Psychiatry 6 (1926): 691.

¹⁵ H. H. Goddard, quoted from S. D. Porteus. The Maze Test (Vineland, New Jersey, 1933).

¹⁶ L. Kanner, "The Exoneration of the Feeble-minded," American Journal of Psychiatry 27 (1941): 98.

¹⁷ Harry J. Baker, Introduction to Exceptional Children (McGraw-Hill, 1940), 52.

¹⁸ Ibid., 101.

¹⁹ President's Report, The Conference on the Care of Dependent Children (Washington, D.C.: U.S. Government Printing Office, 1909).

CHAPTER III

PARENT GROUPS - GRASS ROOTS MOVEMENT

The people is the grand canyon of humanity
and many miles across.
The people is Pandora's box, humpty dumpty, a
clock of doom and an avalanche when it turns
loose.
The people rest on land and weather, on time and
changing winds.
The people have come far and can look back and
say, "We will go farther yet."
The people is a plucked goose and a shorn sheep
of legalized fraud
And the people is one of those mountain slopes
holding a volcano of retribution
Slow in all things, slow in its gathered wrath,
slow in its onward heave,
Slow in its asking: "Where are we now? What
time is it?"

- Carl Sandburg, The People,
Yes (1936)

It was time for the smoldering outrage of handicapped
parents to erupt. It was time to put an end to the rejec-
tions, the indictments, the closed doors and closed faces,
the guilt, the doubt and the despair. The Progressive
Movement had set the stage for the rise of the parents.

Following the 1930 White House Conference on Child
Health and Protection, Elise H. Martens, the Senior Special-
ist in the Education of Exceptional Children Office of
Education, publicly called for the collective action of the
parents:

parents hold the key to the situation in determining how much shall be done in realizing the essentials of a program for exceptional children. For do not parents make the citizens? And do not parents and citizens make the schools? And do they not also choose their legislators? There is no body of people that would have greater weight in promoting provisions for exceptional children than a united group of intelligent, well-informed parents who have the interests of such children at heart. Local study groups have a real opportunity to advance cause, by giving some time to the consideration of their needs, of the nature of the provisions which are being made for them in their own community and State, and of the provisions which should be made for them. Thus, parents will have in their hands a great power toward shaping community attitude, promoting the work of the schools, influencing State legislation, and helping to hasten the time when each one of these exceptional children will have both at home and at school that special care which is needed for

his own welfare and for society's best interest.²

EARLY BEGINNINGS

Parent groups for exceptional children began to emerge as early as 1933. A group of five mothers in Cuyahoga County, Ohio found one another and got together in an "indignation meeting" because their children had been excluded from public school. Out of this protest came the forming of a special class sponsored by the parents themselves to serve excluded children. Elsewhere in Ohio, two years later, a mongoloid child was excluded from school by the local school board. The father, who was a lawyer, took the case to court. It eventually went to the Supreme Court of Ohio where he won his contention that the local school board did not have the right to exclude the child. The publicity the case received rallied other parents around him, and another parent association was formed.

Another parent group formed in Ohio in 1938 when three mothers met by accident while shopping. All had school-aged children who had been excluded from public school because of mental handicaps. They decided to see if they could band together, find other parents with the same problem, and request the local school board to give their children a chance in a specially designed training program. They found nine other parents who were willing to admit openly they had

retarded children. The twelve parents approached the school board and found them surprisingly receptive. This was something the twelve parents had individually been unable to accomplish.³

In 1939 the first parent group for handicapped children in a state school was formed in New York State. A founding member recollected:

It was a beautiful day in the Spring of 1939. It had to be a beautiful day, for this day was set aside by God for the lonesome, forgotten children who were parentless and needed the little kindness which means so very much. Yes, a beautiful day and a day to remember, for on this day a small group of parents took the initiative and obligation to eliminate the word "forgotten" and replace it with the word "remembered." We proposed to the director of the school that parents be allowed to participate in meeting the needs of the children and providing their welfare. Approval of this was granted without hesitation. We would sacrifice our time, money and effort in behalf of the new venture, fully realizing our opportunity to serve in a divine capacity. Our courage and spirit could not be subdued or broken. Despite the

stigma, the misunderstanding, and the almost insurmountable barriers which had confronted us at every turn, we never, for even one moment, forgot the great cause of our efforts--the lonesome, forgotten children who had so little and needed so much. Thus was born the Welfare League for Retarded Children, Inc. at the Letchworth Village State School.⁴

Similar stories of parent group formations began to slowly emerge around the nation. Yet nowhere did parent groups arise with such multitude and fervor as in Chicago. Nowhere did groups emerge representing such a diversity of handicaps. What was unique about Chicago that it was the scene of this phenomenon?

PROGRESSIVE EDUCATION IN CHICAGO

Chicago was a key city in the emergence of Industrial America. Its access to the Great Lakes for water transportation enhanced its position as a railroad terminal for cattle and grain exports. Its flourishing trade, commerce, and industry swelled its population to a million people in the 1880s, making it the second largest city in America.

Its success was due to such industrialists as Marshall Field, Cyrus McCormick and George Pullman, who had wealth and held power. Its success as a leading city was no less

due to the leaders of educational reform who also descended upon Chicago. Among them were Francis Wayland Parker, who came in 1883 as principal of Cook County Normal School; Jane Adams, who started Hull House in 1889; William Rainey Harper, who founded the University of Chicago in 1892; and John Dewey, who chaired the University's philosophy department to 1904.

William J. Bogan, Superintendent of Chicago Schools during the 1930s, recalled the contributions three reformers made to the Chicago Schools:

In Chicago the names of Francis W. Parker, William W. Speer, and John Dewey come to mind whenever genuine progress in education is discussed. Though they were not products of Chicago, they did their most valuable work for the schools while in Chicago. . . . For years these men were the cynosure of educational eyes in all parts of the world. Visitors flocked to Chicago by the thousands to observe the application of their theories. It is significant and encouraging that these great educational leaders, like great poets, were very democratic. It is a serious reflection upon Chicago ideals that these great men met with much opposition from the educational world--the world of their day--but their spirit, luckily for the children

of the new day, goes marching on. Now the schools of Chicago are permeated by the democratic ideals of these great leaders in education. Permission is not only freely granted for every well-planned experiment, but leaders with the gift of inspiration are commandeered for service from other systems. Leadership rather than drivership is the order of the day.⁵

PROGRESSIVE SPECIAL EDUCATION IN CHICAGO

Chicago aggressively assumed the leadership role in the provision of special education programs as well. By 1935 Chicago boasted a wide variety of special classes and schools. The specialized programs included handicapped nursery schools, progressive education experiments, and classes for crippled, anemic, hard of hearing, blind, and mentally handicapped children. In addition, Chicago established the first special school for truant boys as well as a residential school for the more severe truant incorrigibles. Chicago's special education programs also benefited greatly from liaisons with outside agencies who took an interest in Chicago Public Schools. Chicago was a showcase to be emulated by visiting special educators from around the country. Edward H. Stullken, principal of the Montefiore School for Unadjusted Boys, outlined the special programs for a group of such visitors. (See Appendix A.)

A true recipient of Progressivism, Chicago's abundance of special education programs and involved social agencies created the atmosphere in which parents of handicapped children could readily find each other. And when they did, their common needs and frustrations moved them to assemble. Nationally, one of the barriers to the formations of parent groups had been the feelings of isolation and the tendency to keep the problems hidden as guilty secrets. But in Chicago, a myriad of programs put the parents in touch with each other. Problems were exposed and realities were admitted. As the locations of programs and services throughout the city were geographically dispersed, so too were the formations of the parent groups.

BACKGROUND AND ROOTS OF THE FIRST CHICAGO GROUPS

In 1939 a group of volunteers were conducting a nursery school for children with cerebral palsy at the Spalding School for Crippled Children. When it appeared that the nursery school might not be able to continue, the parents of the children, about twelve in number, decided to continue the project through their own efforts. They formed a group known as the Parents Association for Handicapped Children, which enlisted the help of other groups and individuals towards maintaining and extending the nursery school program. Three years later the Parents Association for Handicapped Children merged with another group, the Spastic Children's Aid, which

had been formed on the south side, and the new organization became the Parents Association for Spastic Children's Aid. In describing its objectives, the association declared:

Every State in the Union has adequate facilities for every type of handicapped child except those afflicted with spastic paralysis. These helpless children are martyrs to a cruel situation which an indifferent society has done little or nothing to remedy. Because they are afflicted with many disabilities they are unable to take advantage of tax-supported treatment or education provided for those who are simply crippled, blind or deaf. All too frequently, these waifs are found in institutions for the feeble-minded even though they have normal and, in some cases, superior intellects. To help remedy this deplorable situation the Parents Association for Spastic Children's Aid was organized . . . by the parents of spastic children. Besides assisting in establishing and maintaining homes for dependent spastic children, this association has the general aim of educating the public concerning the problems of spastic children.⁶

The other Chicago membership association of parents of children with cerebral palsy, the Spastic Paralysis Aid Foundation, was organized in August 1945. The foundation's publicity material explained:

The S.P.A.F. was organized on a nonprofit basis in August 1945 by a group of parents of children with cerebral palsy. Each of the parents had felt isolated in trying to meet the problem of his child. It was not until the child received special treatment and training that the parents realized that there were others with similar problems and that there was much mutual gain to be derived from meeting and talking together about their own children, and more broadly, about the welfare of all children with cerebral palsy.

The aim of the foundation was to seek out those children who were handicapped with cerebral palsy and give direct aid to them and their parents by: (1) directing children not under treatment to competent facilities for diagnosis and treatment; (2) bringing the parents together to share mutual problems; and (3) providing equipment and scholarships for those handicapped children whose parents were financially in need.⁷

The Parents' Group of the Chicago Hearing Society was organized in the spring of 1947, but it was preceded by other

group activities at the society in which the organizing members had been involved. In January 1945, Mrs. Spencer Tracy, wife of the movie actor, and herself the mother of a deaf child, spoke at a gathering of four hundred parents, agency representatives, and others, under the auspices of the hearing society. Mrs. Tracy told of her educational work with deaf and hard-of-hearing children and their parents at the John Tracy Clinic in Los Angeles, of which she was the head. One of the major points of interest was the help given to parents of preschool children in the facilitating of their training. The following summer the first Institute for Mothers of Preschool Deaf Children was held at the Jacksonville School for the Deaf, employing some of the Tracy techniques, and including some mothers from Chicago.

In October 1946 some of these mothers began to attend a newly formed class given at the hearing society headquarters by Dr. Jean Utley, Associate Director, Speech and Hearing Clinic of the University of Illinois. It was these mothers who formed the nucleus of the Parents' Group of the Chicago Hearing Society. The society's news bulletin reported the development as follows:

More and more, the importance of parent education is being stressed. This is of particular importance in our field because of the specialized education necessary for the children and the need for an early

understanding on the part of the parent in order that the child can receive the best possible help in the home. It is for this reason that the organization of the Parents' Group is hailed with such enthusiasm.

The first Institute for Mothers of Preschool Blind children organized in 1947. The first president of the organization explained:

We as parents took the initiative in organizing our group, but from the very beginning we felt the need of having representatives from the Division of the Blind on our executive board. Our purpose is to bring the parents of blind children together for mutual interchange of ideas and techniques used in the training of their children. Likewise, in order to help parents receive a sound philosophy of adjustment to their child's handicap, we had selected experts from various fields of medicine, education and social welfare to speak to our group.⁹

Five Chicago groups of parents of mentally handicapped children formed in various parts of the city. The oldest group, at the Association House, was organized in 1948. According to Alfred Rath, Head Resident of the Association House:

A group of mothers of mentally subnormal children started looking for a place in which their children could be taught. Some of the parents had repeatedly taken their children to our public schools only to be told, "Your child is not ready for school yet." Our schools could not accommodate them, since they had been classified as uneducable. Since the parents could not afford the high tuitions of private schools their children could only receive schooling by being sent to overcrowded state institutions. Some of them had previously done so and had not been satisfied with the care or training they received. Many felt their children would not be happy in such institutions. No other alternative existed for these parents except to keep their children at home. No facilities were available that were specifically adapted to help parents train or adjust to these children in the home.¹⁰

The parents of these children discussed the matter among themselves, and then sought advice from a leader of the neighborhood Lion's Club who referred them to Alfred Rath at the Association House. Rath helped the parents in a series of meetings, steering them towards the formation of an

experimental school for a selected group of mentally retarded children. From its inception the group was known as the Retarded Children's Educational Project. The parent group was part and parcel of the project, but it was in existence before the school actually developed in the fall of 1949.

Parents from other neighborhoods and from the suburbs, observing and participating in the Association House program, undertook for reasons of convenience to form their own groups. They had the advice of Rath and of staff members of the Illinois Commission for Handicapped Children which, in the absence of a specialized agency concerned with mentally handicapped children in the community, lent its aid to these parents. The Commission had already conducted its Institute for Parents of Preschool Mentally Retarded Children.

The South Side Parent Group was formed in January 1950. Stated in its constitution, its purposes included: (1) educating the public and the parent regarding the problems of the mentally retarded; (2) bringing together parents and friends of mentally retarded; (3) impressing upon public officials, the Welfare Department, and the general public the urgent need for additional educational facilities for the retarded; and (4) aiding in the development of medical and psychological research on mental retardation.¹¹

INFLUENCE OF SOCIAL AGENCIES

The initial stages of some of the parent groups were guided by professional people associated with social agencies. In several instances the organization of parent groups were stimulated by the previous existence of agency projects. Several educational projects were sponsored by Chicago health and welfare agencies for handicapped children. The Commission for Handicapped Children Project for Parents of Mentally Retarded Children had its origin as follows:

The project was the result of deliberations by a committee of persons interested in mentally handicapped children which was called together by the Elizabeth McCormick Fund of Chicago. The formation of this committee was directly due to: (1) a growing awareness of the unmet needs of the group of mentally retarded children who were not in school or in institutions; (2) increased knowledge of ways in which it is possible to educate these children; and (3) the increasing demand on the part of their parents that some facilities be made available to help them in problems presented in training these children in the home and to

help their children lead more useful and happier lives.¹²

The purpose of the Institute for Parents of the Deaf was stated as such:

Before 1945 much had been done to develop a speech and hearing program in Illinois, but there was still one group not receiving help. That group was made up of mothers--the mothers of deaf children who were not able to get enough medical, educational, and psychological counseling, and many of them were not even able to find out where to get whatever help there was available. In the summer of 1945, therefore, five groups which had been working independently on the development of a speech and hearing program, banded together to see what they could do about helping the mothers of preschool deaf children. They set up a program of adult education. The mothers would come to class with their young deaf children, watch demonstration of training take place, and listen to experts in various phases of deaf child-training. They would go home better able to help the child at home.¹³

The Institute for Parents of the Blind was likewise seen as a means of supplementing individual counseling services:

The home counseling operates on a continuous basis and is the core of this program of parent education, but an Institute was deemed a desirable supplement since: (1) it would make it possible for the mothers to have the benefit of hearing talks by a number of specialists in different aspects of child care and development; (2) a certain psychological advantage might be gained from group participation by some of the mothers who had never seen any blind children other than their own and who had no opportunity to compare notes with other parents with similar problems; (3) the home counseling program served only the mothers in the Chicago area and might not be expected to extend to down-state communities for some time in the future.¹⁴

EDUCATIONAL ACTIVITIES OF THE PARENT GROUPS

The educational activities of the groups were primarily aimed at increasing the knowledge and understanding of the parents themselves. The activities included not only talks, lectures and formal methods of instruction, but also social and informal activities which provided opportunity for the relaxed interchange of ideas and experiences.

The Chicago Hearing Society Parents' Group, which considered itself to be primarily an educational body, almost invariably included a speaker or some other formal educational feature at its regular monthly meeting. The speakers dealt with various problems confronting the parents, such as lip-reading, hearing aids, and emotional adjustment of children. The Director of Education of Exceptional Children of the State Department of Public Instruction spoke on "The State's Plan for the Education of Deaf and Hard of Hearing Children." A pediatrician on the staff of the University of Illinois School of Medicine spoke on "Child Development." There were talks on camps for deaf children, auditory training and the psychological problems of the deaf child. The group also held several panel discussions in which young deaf and hard-of-hearing adults endeavored to help the parents visualize what their children would be like when they grew up. The subjects of such panels were: "What It Means to be a Deaf or Hard-of-Hearing Child," "How to be a Good Parent to a Deaf or Hard-of-Hearing Child," and "Hard-of-Hearing Children."¹⁵

The Parents of the Blind emphasized in its first year the specific aspects of the care of the blind child. Its program, from January to October 1949, included talks by members of various professions on such subjects as "The Nature and Cause of Fibroplasia," "Training the Blind Child," "The Emotional Needs of the Small Child," and "Living in

Blindness." There were inspirational talks by a blind musician and choir director, and by a blind mother on "How I Train my Blind Child." There was also a workshop in braille.¹⁶

Among the topics discussed by professional experts at meetings of the Parents Association for Spastic Children's Aid were speech therapy, occupational therapy, physiotherapy, psychological tests, schools and clinics for the cerebral palsied, and care of the eyes.

The parent groups of retarded children also placed a major emphasis upon lectures and discussions. Particular interest was shown in the causes of mental deficiency, psychological testing, facilities and services for retarded children, play therapy, and the emotional needs of children. One father of a mentally retarded girl clearly recalled his first meeting:

It was a weekday evening in 1950 in a hall at the South Shore Y.M.C.A. in Chicago. About 150 people gathered together for the regular monthly meeting of the Chicago's South Side Parent Group. Most of us were parents of mentally retarded children. Others were relatives, friends, and interested professional people. About one-third of us were fathers. The chairperson of the evening was herself the mother of a mentally retarded

child and the wife of an optometrist. She presided over a very spirited session that lasted about two hours. Before the meeting was over we heard a talk by a physician and by a specialist in mental retardation. We flooded him with questions about mental retardation. We wanted to know its causes and symptoms. His replies were direct and were characterized by rare good humor. I felt so grateful for the information and even more grateful for the touch of lightheartedness.¹⁷

SERVICE PROGRAMS AND FUND-RAISING EFFORTS

In addition to the interest in education shown by the members of the parent groups, there was intensive participation in fund-raising efforts to provide services for the handicapped children.

The Parents Association for Spastic Children's Aid started out in 1942 by conducting its own nursery school for children of members and others. Later, when the public school system established its own program for such children at Spalding, the association aided by providing equipment. A summer camp experiment was conducted in 1945, children being sent to camps for several weeks at the expense of the association. In 1946 a camp was purchased at Pistakee Lake,

Illinois for \$18,000.00 which accommodated twenty children that year, and thirty children in 1947. The camp was then considered too small and was sold. A new and larger camp, Shady Oaks Farm, was opened during the summer of 1948.

In February 1950 the association's Ruth Lodge Residential School for Spastic Children was opened on the north side near Lake Michigan. The school operated on a five-day week except during July and August when the children attended Shady Oaks Camp.¹⁸

To raise the large sums of money, the association demanded very active participation of its members. A founding member recalled the hard work involved:

We held parties, bazaars, rummage sales, bingo games, and drawings on cars and other merchandise. We were certainly creative in our fund-raising efforts. We were determined to make a lot of money.¹⁹

The association also had great success in obtaining the interest of other organizations in its activities. The Ruth Lodge for Spastic Children, a service club, donated the residential school building, valued at fifty thousand dollars, and assumed the mortgage and interest costs. One of the officers of the association was an official of the American Federation of Labor, and was able to secure services of plumbers, painters, and other union craftsmen without charge in the remodeling of the residential school. The

direct income of the association, through its own fund-raising efforts, amounted to at least forty thousand dollars a year from 1948 to 1950.

The chief activity of the associations of parents of mentally retarded children was directed toward the establishment of schools for children not accepted into the public educational system. For the most part, this meant children with I.Q.s below fifty. The example was set by the Retarded Children's Educational Project at Association House, which included both a school and the parent group. All parents whose children were accepted into the school were required to join the parent group. The parents made some financial contributions at the start, and later raised money through rummage sales. Other funds were provided by the neighborhood Lions Club, the Chicago Presbyterian Church Extension Board, and the Community Fund. Parents who could afford to do so paid twenty dollars a month tuition. The following policies were established in relation to the school:

1. The parent group would have an opportunity to observe the methods used at the school and to learn how they might help in their work with the child at home.
2. There would continue to be regular meetings of the parents to further their study of the problem in its broad

ramifications, to exchange experiences and to get advice from specialists.²⁰

By 1950 neither the Parents of the Blind nor the Chicago Hearing Society Parents' Group had developed any service projects of their own.

LEGISLATIVE ACTIVITIES

All of the groups indicated their concern with legislation through either the establishment of legislative committees or through an invitation to speakers on legislative committees. Their lobbying efforts in the past had paid off. The Illinois Commission for Handicapped Children had defined an educable mentally handicapped child as any child whose rate of mental development, as measured by individual psychological examination, has been retarded from birth or early age, but who requires and may be expected to benefit from special educational facilities designed to make him economically useful and socially adjusted. Through the efforts of many of these parents, in 1943 the 63rd General Assembly took steps to provide for the educational opportunity of this group of children. They passed legislation in the form of an Enabling Act whereby public school districts in Illinois could provide an adjusted program that would help the educably handicapped to take their places socially and vocationally in society. The law also provided that the district would be reimbursed by the state for the

excess cost of the program up to a maximum of one hundred dollars per eligible child in an approved program. Due again to the lobbying efforts of the parents of the blind and deaf, in 1945 this act was further amended to include deaf, hard of hearing, blind and visually defective children under the provisions for the physically handicapped. The amendment in 1945 made all the aforementioned groups eligible for three hundred dollars maximum state aid per child.²¹

THERAPEUTIC VALUES

The parent groups of all varieties appeared to offer great help to their members in overcoming the feelings of isolation and the sense of frustration associated with parenting a handicapped child. The group approach to facing the inherent problems offered the advantage of reaching numbers of parents simultaneously, in a supportive, relaxed atmosphere. A founding father of one of the mentally retarded groups expressed his feelings as such:

By listening to others, my wife's and my conflicts seemed to lose some of their strength. It was easy to freely ask, "Why isn't my child walking?," or "Why can't she hold her toys?" We felt so sure of sympathetic understanding from the group. In such a situation, there was such a keen desire to help each other out.²²

A founding mother of a cerebral palsy group recalled:

I was six years old when my mother sent me down the street to borrow a cup of sugar. We knew the family had a hydrocephalic son, but we had never seen the boy. We heard they kept him hidden. The door was slightly ajar when I got there, so I just walked in. The son was sitting right there in his wheelchair. Just then his mother came into the room. She started yelling, and pushed the boy into the cupboard where they kept him hidden. That was seventy years ago, and I remember that as if it happened today. When my physically handicapped daughter was born to me many years later, I vowed that I would never hide her or be ashamed of her. I was active right from the start with that parent group. I'm still active today, and my daughter is grown. You get lots of strength being among friends like that.²³

A report describing the therapeutic values of a parent group program for blind children proclaimed:

There is great therapeutic value for parents in the feeling that they belong to a group, just as there is security for a child in knowing that he belongs to a family. This

feeling of security which comes from being part of a group cannot be stressed too strongly. Nor can we truly appreciate the release, both physical and emotional, that comes when for the first time the mother knows that people will not look at her and her child with a curious expression and does not have to wonder what they will say.²⁴

The rise of the Chicago parent groups for handicapped children during the 1940s represented a growing and dynamic movement that was beginning to burgeon in cities and towns across the nation. The decade of the 1950s would witness the coming together of parent groups into national organizations. What had been accomplished individually would multiply a thousand-fold as parent groups would join together their forces. This act would be a healing one. The sharing of common problems, needs, and experiences would move from the nursing of "wounded parenthood" to concern for the broadened effort of dealing with the problem of handicapped children everywhere.

CHAPTER THREE NOTES

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¹² Illinois Commission on Handicapped Children, "Report on Project for Parents of Mentally Retarded Children," February 1950.

¹³ Illinois Annual School for Mothers of Deaf Children, If You Have a Deaf Child (Urbana: University of Illinois Press, 1949), 3.

¹⁴ Miller, Outlook for the Blind, 154.

¹⁵ News of the Chicago Hearing Society, March-April 1948, 2-3.

¹⁶ Miller, Outlook for the Blind, 170-171.

¹⁷ Irving Maslov, interview by author, Tape recording, Skokie, Illinois, 12 December 1988.

¹⁸ Circular of the Spastic Paralysis Aid Foundation (1950) in Coordinating Council for Handicapped Children, Files, Chicago, Illinois.

¹⁹ Grace Usak, interview by author, Telephone conversation, Chicago, Illinois, 4 May 1987.

²⁰ Summary Statement on Retarded Children's Educational Project prepared by Association House (1950) in Coordinating Council for Handicapped Children, Files, Chicago, Illinois.

²¹ Ray Graham, "The Illinois Program of Special Education in Public Schools for the Educable Mentally Handicapped Children," American Journal of Mental Deficiency 51, no. 3 (1947): 461.

²² Irving Maslov interview, 12 December 1988.

²³ Grace Usak interview, 4 May 1987.

²⁴ Frances E. Marshall, "Group Work with Parents," The Blind Preschool Child (New York: American Foundation for the Blind, 1947), 26-27.

CHAPTER IV

THE 1950s: DECADE OF CHANGE

The merciful mission of parents has created a new attitude toward the entire problem of the retarded people. It has given impetus to a strong movement for hope, betterment and progress. The children have been blessed by the work of the parents, and the parents in turn have been blessed because of the happiness they have derived. The added reward should now be evident. No longer does a parent stand alone. The terrific impact of the misfortune and sorrow has been greatly lifted. There are friends ready to meet the newcomer to help and console him. Hopelessness has been eliminated. The future is beginning to hold promise. The awful stigma is gradually erased. The spirit of parent participation has caught on like wildfire. . . . A brighter era appears on the horizon for handicapped children and their families. Thank God.¹

- Saul Fliederbaum
(1951)

On 6 August 1945, a single plane dropped a single bomb on Hiroshima; eight days later Germany surrendered, followed by Japan on 2 September. The war was won, but peace was not. Yet to come was: the Cold War and the Berlin air lift (1948); the Korean "police action" (1950-1953); and a commitment to Southeastern Asia (1954).

Following World War II, an expanded federal government retained an interest in the economic health and well-being of the country by providing farm price support, low-interest G.I. loans, and continued minimum wages. In 1946

the Congress welcomed three new members to its rank: John F. Kennedy, Richard M. Nixon, and Lyndon B. Johnson.

Jackie Robinson joined the Dodgers baseball team in 1945, signalling a major advance in racial relations in America. The Supreme Court's decision in Brown v. Board of Education (1954) that "separate facilities are inherently unequal" set forth new directions on a constitutional basis in the educational provisions of opportunities for minority youth.

The decades of the 1940s and 1950s, initially motivated by the needs of war, saw a renaissance in science--miracle drugs, nuclear fission, the laser beam, the Salk vaccine, microelectronics, and television. During the 1950s the United States was especially prosperous, producing half of the world's oil, half of its automobiles, and forty percent of its industrial output. All in all, it was a time of prosperity with a promising, though occasionally frightening future.²

For parents of the handicapped, the 1950s brought a new lease on life. Parents no longer needed to hide their children. They no longer felt the necessity of keeping their problems to themselves. They began to accept their handicapped children for what they were, and strove to provide opportunities which would contribute to their happiness and development. Parents began helping the society which had long perpetrated myths and frauds about

recognizing the rights of handicapped children to life, opportunity, and the pursuit of happiness.

Society's change in attitude toward the handicapped was the result of frank expressions by parents who openly revealed the feelings and anxieties they experienced as they adjusted to their new family situation. Pearl Buck, Dale Evans Rogers, and others flooded the media with their own heart-rending experiences as parents of handicapped children. Other parents expressed similar feelings at parents' meetings and in private interviews. Such expressions of feeling helped to clarify many of the problems faced by parents of handicapped children. Gradually those whose actions so greatly impacted on the handicapped: teachers, doctors, and parents of normal children, began to examine their own biases and attitudes.

Parents realized that only by banding together could they bring about the widespread changes in society which were needed. Legislators and other government leaders listened to groups when they would not listen to individuals. Therefore, in order to exercise their newly emerging clout, parents of the handicapped began to unite nationally.

The 1950s would be the decade that people everywhere would become interested in the problems of handicapped children and their parents. National parent organizations, bombardment of the media, and candid expression by the

parents would awaken physicians, educators, and the general public to alleviating society's barriers to the handicapped child's welfare.

NATIONAL ORGANIZATIONS

National Association for Retarded Citizens (NARC)

Though parent groups representing various handicaps began forming locally throughout the 1940s, only those of the mentally handicapped grew with great proliferation. By 1950 eighty-eight such local groups with a total membership of 19,300 had been established in nineteen states. Parents of mentally handicapped children had an opportunity to gather together and discuss their mutual problems at the annual meetings of the American Association on Mental Deficiency in 1947, 1949, and 1950. During the last meeting the parents considered the development of a national parent association and scheduled their first convention for Minneapolis in September 1950.³

The preceding decades had taken their toll in creating an image of the mentally retarded individual as a destructive menace with a child's mind in a grown body. The new organization attacked that image at its most vulnerable point--the child. The tone was set at this first convention when Governor Youngdahl of Minnesota delivered a deeply moving address on the theme of the retarded child:

The human being is an individual whose value cannot be measured adequately in terms of materialism, usefulness to the State, physical fitness or mental capacity. The retarded child has the same rights that children everywhere have. He has the same right to happiness, the same right to play, the right to companionship, the right to be respected, the right to develop to the fullest extent within his capacities, and the right to love and affection. He has the rights for one simple reason--he is a child, and we cannot discriminate against this child, deny to this child the rights of other children because of the one thing neither he nor his family can help--because he is retarded.⁴

Subsequently, Parents and Friends of Mentally Retarded Children, later known as National Association for Retarded Citizens (NARC) was created. Their first major publication, a national newspaper entitled Children Limited served as a means for communicating with the various groups and interested parents and professionals throughout the country.⁵

In addition to providing support and guidance among themselves and in promoting legislation and other

activities to stimulate the development of appropriate programming, many local groups directly sponsored a specific project, frequently to aid the trainable child living at home. In 1955 the association conducted a survey and found that an estimated 1,015 community services directly benefiting mentally retarded persons and their families were operated by its 412 member units. Services most frequently operated by local units included classes for children, recreation and social groups, counseling and guidance programs for parents, sheltered workshops, and special clinics.⁶

National Society for Crippled Children and Adults (NSCCA)

The National Society for Crippled Children and Adults (NSCCA) established a national cerebral palsy parents' council with 150 local parent associations in the latter half of 1949. This council, comprised of parents of cerebral palsied children, was appointed by the National Society's president "to help bring about unification of the many activities carried out on behalf of the nation's cerebral palsied." The society expended a vast amount of energy on parent education, including the publication of educational material and the encouragement of formations of local parent groups as adjuncts to state and local affiliates of the society.⁷

As both NARC and N.S.C.C.A. were large in number and loud in voice, the uniting of parents into national

organizations caught fire in the early 1950s and spread wildly as parents representing a variety of handicapping conditions became eager to assemble. Even parents of children with very rare diseases formed groups in the hopes of squelching their children's desperate feelings of isolation and hopelessness.

Dysautonomia Foundation Inc.

Dysautonomia was discovered in 1948, almost accidentally, by Dr. Conrad Riley when two children with the same peculiar set of symptoms were hospitalized at Columbia Presbyterian Hospital in New York at the same time on the same floor. Dr. Riley was fascinated by the unusual nature of the symptoms: neither child felt pain, nor cried with tears. With no known diagnosis, Dr. Riley began an investigation and found a report by another physician describing case histories of five other children which were strikingly similar to his two patients. Subsequent investigations revealed thirty other children in the New York area with like symptoms. Dysautonomia became a medically identifiable disease, and Dr. Riley brought together the parents of the afflicted children. Thus began the Dysautonomia Foundation.

After three years of merely talking about their problems, the parents were determined to do something for their children. In 1951 the parents formally incorporated the support group, established its medical advisory board

and directed their efforts toward fund-raising to underwrite research.⁸

Muscular Dystrophy Association of America, Inc. (MDAA)

As late as 1950, very little was being done about dystrophy. In that year, however, a small group of parents whose children had been stricken by the disease in New York formed the Muscular Dystrophy Associations of America, Inc. The parents refused to accept the prevailing medical fatalism about the disease, and were determined to raise money to support research in the almost neglected field of muscular disorders. The parents sought out one of the few scientists conducting related research at the time, Dr. Ade T. Milhorat, and with his advice organized the association. Almost immediately after MDAA was founded, chapter affiliates were created in other parts of the country.⁹

Parents Auxiliary of the Little People of America (LPA)

The LPA began in 1957 when television and movie personality Billy Barty organized a group of twenty little people at Reno, Nevada. Its purpose was for parents of dwarfed children to give and receive moral support, as well as to share problems and solutions. It was hoped that through the Parents Auxiliary, adult little people would help normal sized adults with their dwarfed children ("Little-Littles") to adjust and be able to lead normal lives. Fundraising efforts aided vocational training for

little people as well as medical and scientific research in causes and possible treatment of dwarfism.¹⁰

The International Parents' Organization (IPO)

The IPO was the progeny of one of its charter affiliates, the Massachusetts Parents' Association for the Deaf and Hard of Hearing, and of Alexander Graham Bell himself. Less than a decade after establishing the Alexander Graham Bell Association for the Deaf (AGBAD) in 1890, Bell advocated that the parents of hearing impaired children organize to achieve their common goals. In 1956 the Massachusetts state group recognized the need to expand Bell's mandate to a national organization. The organization's charter was to advance oral language through the application of speech, lip reading, and to maximize auditory experience to fill the gap caused by hearing loss. The express goal was to provide a central clearing house at the IPO headquarters in Washington, D.C. for the exchange of useful information on hearing impairment. With that goal achieved, Bell's credo when he founded AGBAD was realized: "No child be denied the benefit of persistent efforts to speak and read lips."¹¹

Thus the 1950s witnessed the developments of a myriad of national organizations for parents of handicapped children. Formation of such groups was not always easy. The inherent difficulties were exposed at a meeting of the American Association of Mental Deficiency in 1950 by Edith

Stern, outspoken advocate for handicapped causes in the 1950s, and herself the mother of a mentally handicapped child. According to Stern local interest and splinter groups made it difficult to develop a sense of national oneness. Unearthing the more emotional difficulties experienced by parents of all types of handicapped children Stern revealed:

It is my impression some parents do not make enough effort to interest others, without any personal concern with mental deficiency, in their groups, and so may lose out on a great potential for public support. The reasons why there may be this failure to enlist others in our cause are all too clear. We parents of retarded children have so great a sorrow that it is hard for us to believe that anyone but parents of similar children could possibly realize it to the extent of wanting to help. Then too, we are inhibited by that sense of shame from which all of us are free among ourselves but which requires hard won adjustment before we are free of it among others. We must not, however, overlook the innate goodness and kindness

of people, who respond when they are shown
a need.¹²

Edith Stern felt the time was ripe for the general public to demonstrate that it would indeed respond with goodness and kindness to a shown need; the too often deplorable, heartbreaking conditions of the handicapped. She would be one of the outspoken writers of the late 1940s and early 1950s who would bombard the heretofore virgin soil of women's magazines with conditions only previously known to those involved in the handicapped community.

MEDIA BLITZ

In a speech presented in May 1950 Edith Stern thanked the editor of The Woman's Home Companion, a widely read monthly magazine, for "the vision and humanity in breaking a long, long taboo on the subject" in publishing articles on mental deficiency.¹³ During the previous year and a half women had found juxtaposed among gardening tips, recipes, and the latest fashion trends the pathetically shocking details of the handicapped world. For many readers, exposure to these conditions was a first and tortuous view. For families of the handicapped it was a long-awaited catharsis.

"It COULD be your next baby--feeble-mindedness strikes in the finest families. Yet thousands of such children and adults still live almost like animals in inferior

institutions. With proper care and training many of them could learn to take respected and self-supporting places in society."¹⁴ So began a story entitled, "Take Them Off the Human Scrap Heap," a depiction of the inhumane conditions Stern witnessed as she visited several institutions:

Built for four hundred and fifty, the institution houses seven hundred. Beds are so tightly packed that the head of one touches the foot of the next. And nothing else in the bedrooms except an array of mops in two dormitories and a can of talcum powder and an artificial flower on a window sill in another. Some of the girls who work at night were asleep in shadeless daylight glare.

The girls' playroom--toyless--boasted double rows of wooden benches along the walls. Some children could not find room even on these and were sprawled on the floor. In the playroom for the most backward boys--called the low-grade boys--I saw exactly one plaything: a string of spools around an old man's neck. In the playroom for brighter boys--highgrades, most of them young--were a set of jacks, a torn comic book and a few tin dolls' dishes.

But I did not see the playrooms at their worst until mealtime. Children considered incapable of going to the dining room were fed in the playroom. Over-worked attendants dished food out of chipped enamel containers and tried to feed the most infantile. The other children either half-sat at tables, wolfing their food from spoons or cupped hands, or ate while pacing the narrow lane between the tables and the wall benches. Conditions weren't much better in the dining room for the brighter children. These children receive no table training. The only utensils were spoons, and here as in every other state training school I visited, there were no napkins. When a child empties his plate and wants seconds the food remaining on some other child's plate is dumped into his.¹⁵

Stern told of another institution where she observed what was politely referred to as "restraint." An epileptic boy was living in a straight jacket though doctors said movement should be free during seizures. Elsewhere she came across two girls tied "like dogs on leashes," one end of a rope around their waists, another attached to a hook on the wall. Furthermore, the brighter boys and girls were

sometimes disciplined by being placed in "untidy wards," as they were called, wards for low-grade children unable to control their toileting needs. In a dayroom of a locked "security" building Stern experienced the possibilities that existed when only somebody cared:

In the dayroom I found a handsome blond boy of about twenty curled on the floor.

"Is he sick?" I inquired.

"Oh, no," the attendant said. "Jimmie likes to be there."

"You don't look very comfortable, Jimmie," I said.

Jimmie grinned, sat up and pulled a stub of pencil out of his overalls.

"Would you like some paper?" I asked. He nodded eagerly so I pulled some blank pages out of my notebook and gave them to him.

"Jimmie can't write," said the attendant.

"Well, he can have fun scribbling," I replied, thinking of the reams of paper my own children had happily covered with scrawls during their pre-school days. And Jimmie did have fun scribbling. Not only that, he began behaving quite normally. He pulled a chair up to a table and sat down.¹⁶

Stern also described instances when those who would have been institutionalized were instead successfully placed in foster homes. She urged her readers to either find a place in their hearts to consider such an undertaking, or at the very least to lobby for additional money and legislation:

American women can demand that their state legislature greatly increase appropriations, and they must be willing to pay a few cents extra for taxes that ensure children in all state training schools receive real training and good care. The investment will pay off well--not only in spiritual satisfaction but in actual salvage of human beings.¹⁷

Continuing on in her public appeal for action on behalf of the handicapped, Stern published two more articles the following year. Each decried sadly the pathetic conditions which yearned for massive public support and outcry. Both left the reader with little doubt that society could no longer simply turn away from prevailing conditions.

By 1949 most states had abandoned the notions of restricted marriage and sterilization as a primary means of controlling future generations of mentally retarded persons. The increasing number of mentally retarded

persons identified, the proliferation of special programs, revised expectancies concerning the stability of IQ scores and heredity, and lack of public and legislative support for these archaic practices rendered such efforts impracticable. There was also growing opposition to sterilization as a substitute for the adequate supervision of young adult retarded men and women in the community. Due to some muddled laws on sterilization there were exceptions. Once again Stern revealed these to the public.

How many wrong guesses have been made about the nearly fifty thousand boys, girls, men and women who have been sterilized to date? Were they really undesirable parents? Certainly Jack is a tragic example of one mistake. Some years ago Jack was a "mischief maker" and "difficult to handle" in an Oklahoma orphans' home. Without the sanction of any psychological tests, he was shipped to the state institution for the feeble-minded. There as a purely routine matter he was sterilized. During World War II Jack enlisted in the army, rose to the rank of master sergeant and became a tank mechanic of considerable ability. After the war he started his own business. Meanwhile Jack had married a normal young woman

who very much wanted a child. Eventually he was compelled to tell her what had been done to him. She got a divorce.¹⁸

The article related other glaring mistakes that had been made in the name of removing hereditary taints from society. Stern gave the example of Grace who was a "graduate" of a midwestern state training school and who had recently written to its superintendent:

Since I am out of the school I have been a good girl. For three years I had the same job. Then I got married and my husband supports me well. I am very happily married. I get on fine with my neighbors. The only thing is, they have babies and we wish we had a baby too. Just before I left the school I had an operation so I couldn't. Is there any operation I could have now to fix me up so I could? Please answer. My husband and I are so anxious to have a baby and we would take good care of it.¹⁹

Stern warned her readership to open its eyes to the immediate need for state laws regulating sterilization of human beings because "even if improved, these laws could create a dangerous habit of mind. As history has taught us, if a person can be sterilized for eugenic reasons, it

is not too far a step to sterilize for political, social, or even religious causes."²⁰

"Who Will Help These Children?" appeared in Woman's Home Companion eight months later. It was an appeal to the mothers of normal children to work for community services for the mentally handicapped as well as to aid in the establishments of parent groups. Stern likened the community neglect of a group that needs schooling, play, friendship and help in getting employment to leaving victims of infantile paralysis to shift for themselves. Her inspiring expose drew an enormous response from the readers in follow-up letters to the editor:

I cannot tell you how deeply moved I was by Edith Stern's article. You see, I am the mother of a retarded child. Mrs. Stern cites several parents' organizations which are taking up the battle for these children. One has recently been started in New York City. When I first heard of it I was going through a critical period. I found it impossible to face the world. I was hiding myself and my child. Coming together in my situation literally saved me.

- Mrs. S. W., New York

I am the twenty-seven year old mother of three children. The first-born of my twin girls is mentally deficient. Last evening I was particularly depressed when I turned to your article. When I finished reading it I had hope again. I've even had a wild scheme to try to contact other mothers of such children to see if classes such as you describe couldn't be started here.

- Mrs. R. C. Massachusetts²¹

Parents of handicapped children continued to flood the media with accounts of their heartbreaking, yet often inspirational experiences. In 1950 Pearl S. Buck wrote The Child Who Never Grew.²² It was the story of the futile journey she traveled in searching for someone who would offer a ray of hope for her severely mentally retarded daughter. The book was published in its entirety in the May 1950 issue of Ladies Home Journal, where it, according to the editor, "evoked the greatest response of any single issue feature so far this year."²³

The public shame of parenting a handicapped child was beginning to wane. A few months later, a mother of a cerebral palsied daughter's letter and accompanying picture were published in the "letters to the editor" of Ladies Home Journal, a now firmly established forum for mothers of the handicapped:

Cerebral palsy cannot be cured, but it can be improved greatly under treatment. And many new methods are being developed. My daughter, three and a half, is receiving occupational, physical and speech therapy. This snapshot shows her in her specially constructed tricycle. It has a curved sheet-iron back with a six-inch leather belt riveted to the back and buckled under her coat. Her feet are strapped to the wooden soles which take the place of the regular pedals. Her right leg has a brace to the knee. Her hands are tied to the handle bars. Sounds pathetic, doesn't it? But there is nothing pathetic about Janet on this trike. She begs for rides every day. And everyone who sees her, though they may feel a tug at their heart for the braces and the bandages binding her body in, feel also the inspiration that her warmth and brightness and hope engender.²⁴

Two years later, Dale Evans Rogers, country-western performer and wife of Roy Rogers, wrote Angel Unaware, a moving story of little Robbin, who was born with an "appalling" handicap and lived to be only two years old. It was Robbin's story "from heaven" as seen through her own

eyes. Throughout the tale little Robbin described her own pathetic condition:

The doctor who delivered me came back. He brought three children's doctors--and how they did talk! And shake their heads! I heard one of the nurses say, "She has Mongoloid eyes." I wondered what Mongoloid meant. They seemed to think it was something awful. . . . My "muscle tone" was poor, I had trouble swallowing, and I seemed to be listless. The swallowing milk business was bad enough; but when I was three weeks old a doctor examined me and found that I had developed a heart murmur.²⁵

Robbin's condition worsened as she approached her second birthday. She suffered a severe convulsion which left her unable to ever again stand on her own. Robbin told of her rapidly failing health:

I had always had trouble trying to hold up my milk bottle. It was so heavy. Mommy and Ginny got a perfume bottle, sterilized it and put a nipple on it. It was light so that I could hold it in my own hands and drain it dry. . . . Of course, my bones were tiny and weak, and there was that soft spot on my head, which hadn't quite closed.

I was tired most of the time, and they had trouble waking me up after naps in the afternoon. I weighed seventeen pounds five ounces--not much for a baby nearly two years old!²⁶

Rogers explained in her forward that she believed her daughter's tragically short existence on earth was a mission from God:

This is the story of what a baby girl named Robbin Elizabeth accomplished in transforming the lives of the Roy Rogers family. I believe with all my heart that God sent her on a two-year mission to our household, to strengthen us spiritually and to draw us closer together in the knowledge and love and fellowship of God. It has been said that tragedy and sorrow never leave us where they find us. In this instance, both Roy and I are grateful to God for the privilege of learning some great lessons of truth through His tiny messenger, Robbin Elizabeth Rogers. This is Robbin's story. This is what I, her mother, believe she told our Heavenly Father shortly after eight p.m. on August 24, 1952.

The Rogers shared their touching and spiritual story with the public as they entertained across the country. They drew compassion and sympathy from those whose lives had been spared such tragedy. They spread comfort and strength to those parents whose lives were similarly touched by a handicapped child. Parents of handicapped children began to look inside themselves, something they had never truly allowed themselves to do publicly. Thus began the cathartic process of purging their emotions and confronting the toll that raising a handicapped child had taken on them, their marriages, and their families.

PARENTS LOOK WITHIN

Raising normal children in the 1950s more or less followed set patterns with which parents were familiar--kindergarten, school, boy scouts, PTA, music lessons, and summer camp. The appearance of a handicapped child in that culture came as a great shock and presented a set of terrifying emotional problems which were entirely new to the parents. Their emotions seemed to walk a tightrope: fear, anguish, anger and hatred seemed to vie for position with hope, optimism, acceptance and love. Encouraged by the parent groups, and inspired by the outpouring of feelings in magazines and books, parents began to look within. For decades they had fought on behalf of their

children for education, legislation and humane treatment by society. Now it was time to take care of themselves.

Mrs. Max A. Murray, President of the Virginia Association for Retarded Children, spoke for thousands when she addressed what seemed to be the most common problems facing families of the mentally handicapped in her article, "Needs of Parents of Mentally Retarded Children." Parents of children manifesting all types of handicaps could identify with the article. She therefore spoke on behalf of parents of handicapped children everywhere when she said, "The first severe problem which parents of retarded children face is the acceptance of the fact that the child is retarded. Successfully coping with the total problem will center relentlessly about this foremost and basic problem."²⁷ Murray continued with the description of three types of parental reactions to a handicapped child: (1) Mature acknowledgement of the actuality and acceptance of the child; (2) disguises of reality with search for either scapegoats upon which to blame the retardation or the seeking of magic cures; (3) complete denial of the existence of any retardation.

The second problem addressed by Murray was the financial one. She warned that in the low or even middle income group the amount of money required in seeking a diagnosis, providing proper medical care and in later years possibly a special training program, could pose a serious financial

burden affecting all members of the family. She admonished that parents who have difficulty in accepting the diagnosis will often spend sizeable sums going from one doctor to another, from one clinic to another, from one treatment center to another until finally their financial situation becomes critical and their health and general efficiency becomes irreparably damaged. Murray relayed the following illustration of such an occurrence:

Within recent years a middle-aged mother was left a widow with three children, a son and daughter in high school and a microcephalic child of about ten. Her husband had built up a modest estate of approximately \$100,000 which would have enabled the two teenagers to acquire a college education and soon become financially independent in their own right. But because of the mother's overwhelming obsession that something could and must be done for the weaker and more helpless child, the entire estate soon dwindled away in the futile search for the cure which the mother blindly believed was just around the next expensive corner.²⁸

A third problem that parents faced was emotional tension built up by carrying a burden which they could not find possible to share with the world.

Those parents who refuse to admit their child is retarded must carry the double burden of grief and pretense--both of which tend to build within them great dams of emotional turmoil for which there seems to be no release. But even the parents who can and do admit their child's limitations often find it difficult if not almost impossible to share their sorrow because their friends, neighbors, and relatives are hesitant to ask about the child's welfare. In the case of severe physical illness or death we could think it inconceivable if our friends, relatives or neighbors showed no concern for our need--yet in this case where the emotional shock is sometimes even more severe than in death, we are denied the privilege of sharing our grief with those closest to us because of a sense of embarrassment or shame.²⁹

Murray next discussed the theological conflicts which arose in the minds of parents when faced with such a heart-rending situation within their own personal lives. She explained that they can accept death because it is a normal and natural part of life's history. Also broken homes, loss of jobs and economic security, serious injury by

accident are all unfortunate circumstances that are within the realm of possibility to every adult couple. "But to suddenly face the fact that their child is a mental cripple and will remain so throughout life, well--this simply places them outside the providence of God's mercy and justice, or so they often feel--if they can indeed still believe that there is a God."

The next problem addressed was what Murray considered to be the most heart-rending of all, that of seeking a solution to the matter of satisfactory life-time care for the handicapped children who, in many instances will need adult guidance and care throughout their normal life spans.

Very few professional persons can fully appreciate or understand the intense feelings of anxiety and concern on the part of parents over this acute problem of life-time care. The professional person, by the very nature of his training, is primarily concerned with finding a solution to the problem immediately at hand. But the professional person must always keep in mind that with the child's parents the problem is not for "just now" but for always.³⁰

Finally Murray described how inept, inactive and ill-timed was the advice given to parents. She suggested that

these mothers and fathers could be spared much emotional damage and conflict if the professional persons they consulted would have two skills: (1) a comprehensive knowledge of all factors concerning mental retardation so far as they are known; and (2) the ability to counsel parents in a straightforward, honest but gracious manner.

Articles such as Murray's were widely discussed among parents of handicapped children during the 1950s. Parents became more comfortable owning up to the inevitable set of problems they were encountering. Through self-realization and acceptance, they gave themselves permission to deal in an emotionally honest manner with those with whom they were so closely connected--teachers, physicians, and parents of normals. Eventually those "significant others" began responding in kind.

SOCIETY RESPONDS

The tide was turning at last. The prolific growth of national organizations, the mass media appeal to the public, and the candid display of parental emotion all served as social catalysts to modify public attitudes and to stimulate sensitivity from the professional world in a manner previously unachieved. It was time for society to respond to the parents' needs. Articles representing the new-found attitudes of those closely associated with the handicapped community filled the pages of journals:

From a social agency:

Progressive social thinking recognizes that a retarded child should be kept in his natural environment--his own home--rather than in an institution. If we subscribe to this statement, then we must conclude that our first line of defense in mental deficiency as with other social problems is the family unit. The retarded child's security, anxiety, or lack of it, will depend largely on the emotional stability of the home. If he is to develop to his full potential and remain in the community, he must be protected from disturbing interpersonal relationships. To achieve this goal it is most urgent that parents too, receive acceptance and understanding, and are helped to maintain a sense of personal integrity.³¹

From a physician:

It is recognized more and more that professional and at the same time humane attention should be given to the attitudes and feelings of people who are understandably puzzled by the lag in their child's development and progress. Whenever parents are

given an opportunity to express themselves, they invariably air their emotional involvements. . . . We have learned to take them into serious consideration and to treat them as the genuine, deep-seated intrinsic perplexities they are. We have learned to distinguish between abrupt, brutal frankness, and a sympathetic statement of fact, between a dictatorial, take-it-or-leave-it kind of recommendation and the sort of presentation which would appeal to parents as the most constructive and helpful procedure, best suited under the existing circumstances.³²

From a psychiatrist:

The attitude of the particular doctor, whether he be pediatrician or psychiatrist, becomes an integral factor in aiding the parents. To be aware that the parents usually know their child is handicapped and defective and that their anxiety is predominantly an expression of their own internalized conflict, increases the possibility of being of real help to the particular parents. . . . The doctor fulfills his medical responsibility when he quite

frankly states his clinical diagnosis--both in regard to mental and physical status of the child--estimates the probable future difficulties, and recognizes the added burden which such children are to parents. He becomes a physician in the true sense of the word, however, when he recognizes and respects the parents' right to decide what they want to do in terms of their total situation, including their own ambivalence and conflict.³³

From an institution committee:

So that the child may continue to feel that he is an important member of the family unit outside the institution, parents should be invited and encouraged to visit the child frequently. They also should be drawn into the life of the institution, assisting in cottage activities as well as helping to solve some of the problems mutual to the parents and to the cottage staff. Such opportunities to share in these experiences would encourage those parents, who have been prone to abandon their children, to maintain an interest in and contact with their children.³⁴

From a dean of education:

Parents of an exceptional child can help him effectively only by accepting him as he is, without embarrassment, resentment, shame, guilt, or resignation. You, as the classroom teacher, have an important part in helping the parents of your pupils. You are the parents' most active partner in the development of their child. Together, you and the parents plan for the child and meet concrete problems in his development. On your shoulders, then, must fall much of the responsibility for helping the parents of your pupils to accept their youngsters with the love and respect which is the right of all children.³⁵

Throughout the existence of mankind, the handicapped suffered as victims rather than beneficiaries of society's conditioning factors and attitudes. With the close of the nineteenth century the parents of the handicapped grabbed on to the threads of the Progressive Movement and gradually, throughout the next several decades, wove them into a cloak of strength. Through their massive efforts in national parent groups, mass media appeal, and a candid display of need and emotion, the parents, in the 1950s,

brought forth their own zeitgeist: The era of the
handicapped child and his parents had arrived.

CHAPTER FOUR NOTES

¹ Saul Fliederbaum, "Effect of Parent Group Participation in State Schools," American Journal of Mental Deficiency 56 (1951): 184.

² P. Smith, The Nation Comes of Age (New York: McGraw Hill, 1981).

³ W. Hay, "Associations for Mental Retardates," in Encyclopedia Americana, 1952.

⁴ National Association for Retarded Citizens (NARC), Blueprint for a Crusade, (Arlington, Texas: National Association for Retarded Citizens, 1954).

⁵ Parents and Friends of Mentally Retarded Children became known as the National Association for Retarded Citizens in 1954. In 1980 it assumed the title Association for Retarded Citizens of the United States.

⁶ N. Rigler, "Nationwide Survey of Unit Services," American Journal of Mental Deficiency 61 (1956): 432.

⁷ Bulletin of the N.S.C.C.A. (October 1949), 9. Coordinating Council for Handicapped Children Files, Chicago, Illinois.

⁸ "Dysautonomia Foundation Inc.," The Exceptional Parent, September/October 1974, 26.

⁹ "Muscular Dystrophy Associations of America, Inc.," The Exceptional Parent, April/May 1972, 22.

¹⁰ "Parents Auxiliary of the Little People of America," The Exceptional Parent, March/April 1974, 24.

¹¹ "The International Parents' Organization," The Exceptional Parent, March/April 1973, 24.

¹² Edith Stern, "Problems of Organizing Parents' Groups," American Journal of Mental Deficiency 56 (1951): 13.

¹³ Ibid., 11.

¹⁴ Edith Stern, "Take Them Off the Human Scrap Heap," Woman's Home Companion, August 1948, 32.

¹⁵ Ibid., 32.

- ¹⁶ Ibid., 63.
- ¹⁷ Ibid., 64.
- ¹⁸ Edith Stern, "Should Anybody Be Sterilized?" Woman's Home Companion, April 1949, 50.
- ¹⁹ Ibid., 50.
- ²⁰ Ibid., 113.
- ²¹ "Companionably Yours," Woman's Home Companion, February 1950, 12.
- ²² Pearl S. Buck, The Child Who Never Grew (New York: The John Day Company, 1950).
- ²³ "Our Readers Write Us," Ladies Home Journal, August 1950, 8.
- ²⁴ "Our Readers Write Us," Ladies Home Journal, January 1951, 8.
- ²⁵ Dale Evans Rogers, Angel Unaware (New Jersey: Fleming H. Revell Company, 1953).
- ²⁶ Ibid., 40.
- ²⁷ Mrs. Max A. Murray, "Needs of Parents of Mentally Retarded Children," American Journal of Mental Deficiency 63 (1958-59): 1078.
- ²⁸ Ibid., 1080.
- ²⁹ Ibid., 1081.
- ³⁰ Ibid., 1087.
- ³¹ Michael J. Begab, "A Social Work Approach to the Mentally Retarded and Their Families," American Journal of Mental Deficiency 63 (1958-59): 528.
- ³² Leo Kanner, M.D., "Parents' Feelings About Retarded Children," American Journal of Mental Deficiency 57 (1953): 375.
- ³³ S. L. Sheimo, M.D., "Problems in Helping Parents of Mentally Defective and Handicapped Children," American Journal of Mental Deficiency 56 (1951): 45.

³⁴ N. L. Bostock, "The Parent Outlook," American Journal of Mental Deficiency 63 (1958-59): 515.

³⁵ S. R. Laycock, "Helping Parents to Accept Their Exceptional Children," Exceptional Children 18 (1951/1952): 129-130.

EPILOGUE

The decade of the 1950s heralded the turning point for the handicapped community. Parents reacted against centuries of neglect, rejection, and mishandling. In the ensuing years parents and friends of the handicapped have been joined by professionals as effective social change agents, participating jointly in major legislative efforts and landmark litigation. Remarkable advances for the handicapped have been realized over the past thirty years. Throughout these decades two forceful trends have been evident, both of which have held tremendous importance for handicapped citizens: expanded recognition of human and civil rights and substantially increased federal funding of human services and programs.

INSTITUTIONAL REFORM AND DEINSTITUTIONALIZATION

The resident population of state-administered institutions grew from 125,375 to 189,549 between 1950 and 1970.¹ Few institutions had the financial, personnel, or physical resources to meet the needs of residents, and the quality of life continued to deteriorate in many facilities. During the 1970s the federal courts took a major interest in institutions, declaring many of their conditions and procedures unconstitutional. Not only did the courts

declare that certain standards and procedures must be met, but also the American Association on Mental Deficiency developed institutional standards and encouraged the establishment of an independent agency, the Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons.² The tour de force of institutional reforms was the inclusion of mentally retarded persons under the 1971 amendment to Title 19 (Medicaid) of the Social Security Act. Not only did regulations include many of the Accreditation Council's standards, but the federal government also provided critical financial support necessary to ensure their implementation.

Deinstitutionalization was sought as fervently as institutional reform. In order to accomplish this goal institutions had to make a concerted effort to increase the independence of their mentally retarded residents, i.e., preparing them for community placement, and communities, in turn, had to develop the broad array of services essential to maintaining mentally retarded people in the mainstream of society. Deinstitutionalization became a primary objective of the 1970s when President Nixon set a national goal of reducing institutional populations by 30 percent before the turn of the century. Success in this area is reflected in the fact that between 1970 and 1979 the number of residents in state-administered institutions decreased by

50,139 persons, though the country's population continued to increase.³

PUBLIC EDUCATION

Nowhere, however, have the targeted areas for change coalesced more clearly than in the parent inspired advocacy efforts aimed at securing the handicapped child's right to education. The watershed occurred during the 1970s when parents and advocacy groups turned to the courts to establish specific educational rights for students with disabilities. Two federal cases were particularly instrumental in establishing the legal right of these children to an appropriate education. The first, Pennsylvania Association for Retarded Citizens (PARC) v. Commonwealth of Pennsylvania (1971), affirmed the principle that mentally retarded children have the right to a public education. The second, Mills v. Board of Education (1972), extended the right of public education to all children with handicapping conditions (regardless of the nature or severity the disability) and established two important principles: (1) public schools had to provide alternative educational programs to students with disabilities rather than exclude them from school; and (2) school districts could not refuse to provide educational programs for these students because of a lack of resources.

Despite these advances, the educational rights of people with disabilities were neither comprehensive in scope nor geography. There were fifty different American special education systems: some states offered extensive programs while others provided meager help that met legal requirements but dealt with a very narrow range of disabling conditions. It became increasingly clear that only federal action would resolve the wide discrepancy in the quality of special education services nationwide. Congress responded with two landmark legislative acts: Section 504 of the Rehabilitation Act of 1973 and Public Law 94-142, the Education for All Handicapped Children Act of 1975.

By passing the civil rights bill known as Section 504 of the Rehabilitation Act of 1973, Congress expressed a national commitment to eliminate discrimination against the disabled. The bill stipulated that children who have disabilities must receive educational services and opportunities equal to those provided to children who do not. Section 504 also prohibited a school district from excluding students with disabilities from a school that is otherwise appropriate because the building is not physically accessible to them.

Parents of handicapped children have reason to remember 29 November 1975. On that day President Gerald Ford signed into law the Education for All Handicapped

Children Act (Public Law 94-142). Hailed as an educational bill of rights for children with educational disabilities, this federal law not only required that "all handicapped children have available to them a free appropriate public education" but also dramatically expanded parents' roles in their children's education. (See Appendix B.)

The intent of Public Law 94-142, as described in the Act's Statement of Purpose, was to functionally reverse the exclusionary practices of public schools. It was to do so by providing all disabled children, regardless of the nature or severity of their disability, with a free and appropriate public education. Toward this end, the legislation has provided for federal financial and technical assistance to State Educational Agencies which have been in compliance with the implementing regulations of P.L. 94-142. Parents, according to P.L. 94-142, were to play several key roles: as providers of information, as decision makers in the development of their child's educational program, as advocates in asserting their child's interests at a fair hearing and as partners with the school in implementing Individualized Education Plans (IEPs).

The framers of Public Law 94-142 hoped to forge an alliance between parents and schools on behalf of handicapped children. While the passage of the law marked the end of a major class advocacy effort, it imposed upon all parents of the handicapped the formalized role of case

advocate. In asserting that the status of parents on the IEP team be equal to that of professionals, the Act recognized the unique qualifications parents possessed as consultants to their child's educational program and as necessary partners in its implementation.

LOOKING TO THE FUTURE

No other twenty year period witnessed as many humanitarian changes toward the handicapped as did the 1960s and 1970s: rights, mainstreaming, advocacy, individual plans, deinstitutionalization, and local state and federal support from each of government's three branches--executive, legislative, and judicial. Much was accomplished, and countless handicapped individuals benefitted from opportunities never before available. Yet the gains and changes that times has wrought can be credited not only to the battle waged by the parents of the handicapped, but also to a society whose attitudes, sense of responsibility, and human commitment have slowly and consistently grown over the past several decades.

Certainly, the past warns that future progress for handicapped persons is never assured. If current philosophies of the 1980s are maintained then the future is indeed most promising. Yet all such advances will remain contingent upon society's respect for the inherent dignity of all people. The degree to which society serves or

enables others to serve the handicapped is the degree to which society serves itself. In the words of former President John F. Kennedy, "The manner in which our Nation cares for its citizens and conserves its manpower resources is more than an index of its concern for the less fortunate. It is a key to its future."⁴

EPILOGUE NOTES

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² Joint Commission on Accreditation of Hospitals, Standards for Residential Facilities for the Mentally Retarded (Chicago: Joint Commission on Accreditation of Hospitals, 1971).

³ R. Schreenenberger, Public Residential Services for the Mentally Retarded (Madison, Wisconsin: National Association of Superintendents of Public Residential Facilities for the Mentally Retarded, 1980), 39.

⁴ President's Panel on Mental Retardation. A Proposed Program for National Action to Combat Mental Retardation (Washington, D.C.: Superintendent of Documents, 1962), 196.

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APPENDIX A

SPECIAL EDUCATION IN CHICAGO

Edward H. Stullken

Journal of Exceptional ChildrenVol. 2, Pages 73-75, December 1935

Nursery School Education

There are two schools which offer instruction to a small number of pupils from the age of two to four years. One of these, located in the Spalding School for Crippled Children, cares for children with spastic paralysis, and the other, located in the Parker Practice School, is interested in the advantage which nursery-taught children may have in physical development and social adjustment. It is a research school for determining the effect of parent education as well as whether or not children who are taught sound habits of living at this age will show any marked advantage over children reared exclusively in the homes.

Progressive Education Experiments

The Joyce Kilmer, the Lewis-Champlin, and the Smyser provide for the socialization of subject matter, adequate study of the individual child, and creative activity for individual needs.

Schools and Classes for Crippled Children

The provision made for the exceptional needs of physically handicapped children constitute one of the highlights of the Chicago Public Schools. The Chicago Board of Education maintains four centers for crippled children with a membership totaling 1,190. Of these, the Spalding School on the near west side, and the Christopher School on the southwest side serve crippled children of elementary and high school ages. The Jahn School on the north, and the Gompers School on the far south devote part of their buildings to the use of crippled children.

Classes for Anemic Children

A large group of children are educated in Chicago's sixty-eight open-window rooms. These are children of lowered vitality, undernourished, anemic, or with incipient tuberculosis tendencies. Segregated in special classes, they are supplied with Eskimo suits to wear in the lowered room temperature, and with cots and wool blankets for rest periods.

Deaf and Hard-of-Hearing

About five hundred deaf and hard-of-hearing pupils receive special teaching in Chicago public schools. They are in three centers--at Bell, Beidler, and Parker Practice--on the three sides of the city.

Classes for the Blind and Partially Sighted

In 1900 Chicago responded to an awakening national realization that it was enlightened self-interest for society to care for the blind. In that year the first public school class for the blind was opened. Some years later the schools made provisions for the partially sighted. Today there are twenty-seven schools in Chicago offering special classes for the blind and partially sighted.

Rooms for Mentally Retarded

In 164 schools, special rooms for subnormal children make provision for their care. Teachers of subnormal children will find that the Burley School on the north side, the Wadsworth School on the south side, and the Bryant School on the west side have typical examples of the type of work done in Chicago's special divisions for mentally retarded.

Special Schools for Unadjusted Boys

One conspicuous feature of the program of special education is the provision of special schools for truant boys. The first of these schools, the Montefiore, was opened in September 1929, and the second, the Mosely, a year later. These schools enroll approximately nine hundred fifty boys and are designed for those who need special attention educationally, psychologically, and medically. The classes in the schools are small, averaging not over twenty-five boys per class. With small classes and

additional equipment, the teacher is able to give the problem boy the individual attention he needs.

The Chicago Parental School

This is a residential school where truants and incorrigibles are given custodial care when other measures fail. Many special educational features and an extensive farm and home life program are carried on at this institution.

Extra-School Agencies Cooperating with Schools

Many outstanding efforts between Chicago's schools and other agencies can be found in the Chicago school system. Most of these agencies are of service principally in that they furnish services, materials, and workers to help teachers and principals care for the adjustment of the needy child. Examples of these agencies are the various bureaus of the City Department of Health, the Juvenile Court, the Juvenile Protective Agency, the Elizabeth McCormick Memorial Fund, and the various charities, child guidance clinics and hospitals.

APPENDIX B

THE EDUCATION FOR ALL HANDICAPPED CHILDREN ACT OF 1975

PUBLIC LAW 94-142

It is the purpose of this Act to assure that all handicapped children have available to them . . . a free, appropriate public education which emphasizes special education and related services designed to meet their unique needs, to assure that the rights of handicapped children and their parents or guardians are protected, to assist states and localities to provide for the education of all handicapped children, and to assess and assure the effectiveness of efforts to educate handicapped children. (20 U.S.C. 1401)

APPROVAL SHEET

The dissertation submitted by Janis Fine has been read and approved by the following committee:

Dr. Joan K. Smith, Director
Professor, Educational Leadership and Policy Studies; and
Associate Dean, Graduate School, Loyola University of
Chicago

Dr. Max A. Bailey
Associate Professor, Educational Leadership and Policy
Studies, Loyola University of Chicago

Dr. Gerald L. Gutek
Professor, Educational Leadership and Policy Studies,
Acting Dean of School of Education, Loyola University of
Chicago

The final copies have been examined by the director of the dissertation and the signature which appears below verifies the fact that any necessary changes have been incorporated and that the dissertation is now given final approval by the Committee with reference to content and form.

The dissertation is therefore accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

28 March 1989
Date

Joan K. Smith
Director's Signature