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Opening the Eyes of Parents of Visually Handicapped Children: Putting Public Law to Work for You

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PROLOGUE

"I am afraid there is very bad news." The specialist was speaking to my wife, Lynda, and I. It was Tuesday, August 2, 1977 and we had brought our 5 month old daughter for what our doctor had said was a routine check-up. Our daughter, Erin Joy, was born with a cataract in both eyes. (The doctor said that the medical profession called Erin's condition congenital bilateral cataracts.)

Now Lynda and I were sitting in the opthalmologist's outer office hearing him say there may be extremely bad news. What could be wrong? In the space of a heart-beat he told us. "I am afraid your daughter has cancer in her right eye." Cancer, in her right eye? What? Why? How? The doctor was telling us we should see another specialist in a neighboring city for a third opinion. The doctor's next statement brought our full attention back upon him! "If it is cancer, the eye must come out right away." Her eye removed? "What does this mean, doctor?", we asked. He went on to explain that when he examined our daughter's cataracts he was quite sure he saw cancerous tumors in the eye. He brought his partner specialist in for his opinion. They both agreed our daughter had retinoblastoma, an extremely fast-growing cancer that attacks the human eye. If the neighboring city's specialist's tests proved them correct then the entire eyeball must be removed, and quickly.

The next day found us in the other specialist's office, where retinoblastoma was verified. Our precious little 5 month old girl had cancer. Her mother and I felt as though we were swimming in an ocean of great waves that threatened to engulf us.

On Thursday, August 4, 1977, Erin Joy's right eye was enucleated (surgically removed). A new chapter was opening in the lives of my wife, our 4 year old son, Greg, Erin Joy, and myself. It was a chapter we could not anticipate. It was to bring pages we could not before hand see.

It was, in a sense, but the beginning. Seven months later doctors discovered cancer in Erin Joy's one remaining eye. A campaign to save Erin Joy's eye, and, if possible, her sight began. Our family was to undergo many trying times in this battle to save Erin's vision. For a while it became a fight to save her life.

As the parents of any handicapped child can tell you, our entire family life has been colored by Erin Joy's handicap. Many of the decisions we make, the choices we take, are evaluated in the light of this handicap.

The paper that follows is the result of a college research paper assignment. I decided to deal with the topic of the implementation of public law in the United States of America. I chose a law that will have more and more meaning for our family as Erin Joy grows up to school age. The model law for this paper is Public Law 94-142, The Education for All Handicapped Children Act.

The paper will finish with an epilogue that will be a personal case study. It is our prayer that this paper will help to open the eyes of parents of handicapped children to the possibilities of service our society provides the handicapped individual and his family.

In January 1953 the Federal Government was preparing to say good-by to outgoing President Truman and to welcome in-coming President Eisenhower. As President Truman was sorting through and cleaning out his files he said to an aide, "Poor Ike--he'll sit right here and he'll say 'Do this, do that' and nothing will happen. It won't be like the Army. He'll find it very frustrating."

The advocates of a free appropriate public education for the handicapped know the frustration of trying to implement new policies. In 1975, however, a landmark law, P.L. 94-142, began to pave the way for the handicapped children in the United States. This paper will look at the history, policy-making, and implementation of the Education for All Handicapped Children Act, which is also known as Public Law 94-142 . Much of the specifics discussed about this law can be generalized for most laws in this country. Let us begin our study.

A Historical Sketch: Earliest Public Education of the Visually Impaired Child.

In Great Britain. Grade School children in London, England received an eye examination for the first time in the early part of the twentieth century.[1] The first medical director on the London School Board ordered this medical test for eye diseases and visual acuity.

1.His name was Dr. James Kerr and he directed his staff to "Record your findings so that they may be made use of in a general record of the state of the eyes of children, and if your experience suggests some allied investigation, go ahead with that inquiry and count the doing of it a part of your service." (Quotation from Winifred Hathaway's book Education and Health of the Partially Seeing Child, 4th Edition, Columbial University Press, NY, 1959, P.3.)

In 1902 a young man by the name of N. Bishop Harman was appointed director of the ophthamological program of the London schools for the blind. After detailed examinations he found that many of these pupils were not blind but had been placed in the blind schools because of severe myopia (a refractive error for which, to gain clear vision, an object must be closer than 20 feet away from the viewer). In a report to the "Second International Congress of School Hygiene, held in London in 1907 Harman's evaluation was that[2] "since these children were not blind they should not be in an institution for the blind, but, rather, should be given special educational facilities adapted to their needs."

These two men, Dr. Kerr and Mr. Harman, with the support of the educational committee of the London County Council (and with particularly strong support from a Miss Nettie Adler, a member of the Council's educational committee and chair-person of the section of the International Congress which heard Mr. Harman's report), founded, in South London in 1908, the first school in the world that purported to provide education for the visually impaired child.

<u>Other Countries</u>. Testings and evaluations of Children's vision in other parts of the world revealed the same need for reclassification and educational opportunities for visually impaired children. Thus, a class for the visually handicapped was provided in Strasbourg, Germany in 1911. By 1933, classes for the partially seeing child were being held in other German cities as well as Austria, Switzerland, Denmark, and France.

[2] Hathway, P.3.

By 1939 many western and eastern European countries were providing classes within their school systems for visually impaired children.

In The United States. Residential schools for the blind were begun in Massachusetts and New York in 1832 and in Philadelphia in 1833.

It wasn't until 1909, however, that London School System's pioneering efforts of education for the visually impaired gained notice in America. The director of Perkins School for the Blind, an Edward E. Allen, learned of London's innovations while attending a conference in that city. His experience told him this program was critically needed in the United States. From experience as both a teacher and administrator, Mr. Allen knew first-hand the difficulties of the partially seeing child.

In the first place, children who enjoyed some vision almost always developed a superiority complex while being educated with blind students. These superior feelings were quickly shattered when the children left their sheltered surroundings and entered the real world. Often this blow of reality was so shattering the young people could never recover their self-confidence.

Secondly, visually impaired children often became frustrated with two things within the blind schools: (1) the regulations which were necessary for the protection of the blind children that had to be strictly adhered to by the partially seeing student as well, and (2) being used as guides and helpers for the blind children often left the visually impaired child drained, both physically and emotionally. As a result of these frustrations many of these children would drop out of school. They would then face society with a double handicap---restricted vision and little education.

After much work on the part of Mr. Allen and others the first school in the United States for the visually handicapped was opened in the Boston suburb of Roxbury.[3] "These children, unlike those in the London class, were segregated from their companions for all school work." In other parts of the country the idea of separating education for the visually impaired and the blind was being assimilated. Classes were begun in Chicago, Cleveland, New York, and Milwaukee.

In Cleveland, in 1913, the director of the special classes for the blind and partially-seeing, Robert B. Irwin, requested that the two groups be separated and that teaching materials and equipment necessary for the partially-seeing be made available. In September of that year, the Waverly School in Cleveland became the second class in the nation to provide specific education for the visually handicapped. There was an important difference between the direction taken by Cleveland and that taken by Boston, however. In Boston the visually handicapped children were segregated--their learning experience was isolated. In Cleveland, these special children were integrated with normal children for all possible, at that time, education, such as oral work and lectures series. These children went into separate classrooms containing special equipment for their writing work. As school systems around the country began to provide special education for visually handicapped children, some of them went the way of Boston, while other's followed Cleveland's lead.

3 Hathaway, P.7.

Background Information: Policy Making

Historically, democracy has been seen as a protector of personal liberty with little thought given to its policy-making processes. Overlooked, too, is its role of popular control in policy-making. Charles Lindblom, the Peter Drucker of America's policy making system observes that[4] "All over the world, either dominant elites, or masses (pluralist power) appear to want, among other things, law and order, agricultural and industrial production, and mobility and communication. If, through such accomplishments as these, they think they can afford others, they then want increasingly productive technologies, minimum standards of living for almost everyone, and new ventures in research, education (emphasis added), and exploration." Governments set the objectives and follow the policies they do because of these needs and desires of people. The policy-making process explains some of the ways Governments work to achieve their goals, but not always the reasons for the goals themselves. In order to gain an initial understanding of policy-making in the United States, certain questions must be asked and knowledge obtained. To fully understand policy-making one must have a complete and thorough knowledge of the political process in this country. The non-political student must not despair, however, for it is possible to gain a workable understanding of policy-making, and that quite easily.

Let us begin to ask some questions whose answers are pertinent to a functional understanding of this process. How does a law come into being? How does a concern become an issue? How does an

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[4] Charles E. Lindblom, The Policy-Making Process, 2nd Edition, Prentice-Hall,Inc.,Englewood Cliffs, New Jersey, 1980, P.7.

issue move onto the public agenda? What happens then? Who are the policy-makers in America? Answering these and like questions will bring a basic understanding of the policy-making process in this country.

Just who are the policy-makers? Is the ordinary citizen a policy-maker? Can he become one? Any individual can take an active role in policy-making by joining a special interest group. Unless there is involvement in an advocacy group, howver, the typical citizen has next to no influence upon policy in the United States. The policy-makers in our country are mainly found in government and business. In addition, judges, lawyers, bureaucrats, special-interest group leaders, and powerful individuals can be policy-makers with regard to issues affecting them (such as conservation, energy, education, and welfare). For the most part, however, politicians and top business-managers are the stronger policy-makers. A legislator typically believes that the state of the economy is the one issue that can consistently further or harm his career. Therefore, the legislator finds himself in the necessary position of closely monitoring the needs of the business community. It has been said that in terms of regulation, control, and taxes the legislator usually thinks business needs what business-managers think business needs! (See Charles E. Lindblom, The Policy-Making Process).

A concern becomes a political issue by coming to the attention of a policy-maker. He or she then brings this point of dispute to the public agenda. Often, an issue is the result of two or more parties disagreeing over something and being willing to arrive at a compromise solution. This process of working out a solution is policy-making.

When an issue comes onto the public agenda, it is researched, and evaluated (with varying depths of input, depending upon the value of the issue, to whom it is important, and the available time). During the public agenda stage there may be much public discussion (congressional hearings, media coverage, etc.) and cause recruitment (special-interest, business, and governmental groups soliciting public support for 'their side'). Advocacy for the support and defeat of any particular bill often takes place. If the public agenda item (now a bill in Congress committee) receives an affirmative vote in Congress and is signed by the President of the United States, it becomes a Public Law.

One must remember that throughout the life of an issue (from concern to Public Law), many groups will be involved--poking and prodding at the issue, fighting to change, pass, or defeat it.

More often than not a public law is changed from the intent of the parties forming the original issue. Such is the challenge and power of various interest groups. Such is the complexity of our society.

A final word needs to be said here about policy-making. Often, the implementation of one solution causes new problems and issues. We will look more closely at this phoenomenon of American politics--the implementation of public law, shortly. We will use for this purpose a case study, Public Law 94-142, the Education for All Handicapped Children Act of 1975.

Scope and Intent of P.L. 94-142

Public Law 94-142 is the Education for All Handicapped Children Act. This legislation was passed (almost unanimously) by the United States Congress and signed into law by President Gerald R. Ford on November 29, 1975. The '94' means that this law was passed by the 94th Congress and the '142' means it was the 142nd piece of legislation signed into law by President Ford.

P.L. 94-142 has four major purposes:[5]

> "(1) Guarantee the availability of special education programming to handicapped children who require it.
>
> (2) Assure fairness and appropriateness in decision-making about providing special education to handicapped children.
>
> (3) Establish clear management and auditing requirements and procedures regarding special education at all levels of government.
>
> (4) Financially assist the efforts of state and local government through the use of federal funds."

Let us look briefly at each main purpose.

(1) Senate and House committee hearings provided much information that many of the educational needs of handicapped children in this country were unmet. Furthermore, the testimony of educators, handicapped-helping groups, and handicapped individuals strongly indicated these needs would continue to be unserved unless the Federal Government stepped in to undertake legislative action.

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[5] From a pamphlet by Joseph Ballard "Public Law 94-142 and Section 504--"Understanding What They Are and Are Not", available from The Council for Exceptional Children, Reston, Virginia.

Up to this point the Federal Government's involvement was to be a catalyst. In this regard, Congress had passed legislation such as the Elementary and Secondary Education Act, the Education of the Handicapped Act, and The Rehabilitation Act of 1973, and the Education Amendments of 1974. In 1975, however, government was faced with the realization that these laws were not enough to solve the educational discrimination against and segregation of handicapped children.

The matter was forcefully brought to Congress's attention because American citizens were taking school boards to court in order to win just and proper education for handicapped children.

Two landmark court cases were Pennsylvania Association for Retarded Children (PARC) vrs. Pennsylvania, and Mills vrs. Board of Education of District of Columbia. In the PARC case the action won effected retarded children only, but it was a class action suit, meaning that more than one party could benefit from the decision. In Mills vrs. the D.C. Board of Education, Judge Joseph P. Waddy's decision for Mills eventually effected all handicapped children. Judge Waddy's Memorandum Opinion, Judgment and Decree became, in large measure, the language of P.L. 94-142.

[6] "The Court in Mills ordered that:

'No child eligible for a publicly-supported education in the District of Columbia public schools shall be excluded from a regular public school assignment by a rule, policy, or practice of the Board of Education of the District of Columbia or its agents unless such child is provided:

[6] United States Code: Congressional and Administrative News, 94th Congress 1st Session, 1975, Vol.2, West Publishing Co.,St.Paul,Mn., P.1430

(a) adequate alternative educational services suited to the child's needs, which may include special education or tuition grants and,

(b) a Constitutionally adequate prior hearing and periodic review of the child's status, progress, and the adequacy of any educational alternative.'"

(2) Public Law 94-142 attempts to assure fair and appropriate education to the handicapped by introducing several parties into the curriculum planning process. This curriculum plan is called the Individual Education Program (IEP). This IEP must be prepared for each handicapped student and is subject to revision several times each school year.

Taking part in the preparation of each program is a representative of the local educational unit (school district, vocational school district, special school district, etc.), the teacher, the parents or guardian of the child, and, where appropriate, the child himself. This Individual Education Program must be written out. It must show not only where the child is specifically in all areas of education, but also show what the child is to attain in the forseeable future. The IEP must have the parent's or guardian's, and, where appropriate, the child's full agreement to the program.

(3) In order to insure proper management and auditing techniques and to instill accountability to the law, the Congress of the United States assigned sole responsibility for the implementation of P.L. 94-142 to "the State educational agency."[7] Further, the legis-

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7 U.S. Code, p. 1448.

lature went on record as stating that "the establishment of single agency responsibility for assuring the right to education of all handicapped children (is) of paramount importance." Congress further said that the State school officer will take all necessary steps to see that the law is fulfilled. The Commissioner of Education is required to audit and evaluate the performance of all State educational agencies. As we will see later, problems developed in the implementation stage with these "single agency responsibilities".

(4) To discover the exact payment and time schedules that the Government will follow in providing financial support to state and local school districts for the implementation of this law, one may look in the U.S. Code: Congressional and Administrative News, pages 1447, 1462, 1473, 1485, 1486, 1487, and 1504. Suffice it here to say that studies by the National Education Finance Project determined that it will cost twice as much to educate a handicapped child as a normal child. P.L. 94-142 provides that the Federal Government will pay the 'normal cost' plus twenty-five percent of the additional cost of educating each handicapped child. As we shall shortly see, there are implementation difficulties here as well.

Historical Interest, Problems, and Intent Leading Up to P.L. 94-142

Before 1966, when a new title VI was added to the Elementary and Secondary Education Act (P.L. 89-750), the Federal Government had done little to help give direction or support for the education of handicapped children. Those programs which did exist were provided by a large number of different agencies. The whole field of education for the handicapped suffered from the lack of a central, powerful administrative agency. As a result of P.L. 89-750, the Bureau of Education for the Handicapped was set up to give the direction needed in this field. Research and landmark court decisions proved the necessity for a greater Federal role in this area.

In 1975 the Congress of the United States began holding committee meetings regarding the advisability of additional Federal law for the education of the handicapped. The United States heard[8] "testimony from parents, teachers, and experts in special education specifically (emphasizing) the need for the earliest possible identification, evaluation, and service to children prior to their entry into the normal educational process."

It is often much more beneficial to both the child and society for the earliest possible diagnosis of a handicapped condition. With an early discovery the child has a much better opportunity to gain a near normal education. Medical experts, special education equipment and devices, and specially trained personnel can be brought into the case to help improve, correct, or alter the disabling condition so that, by school age, the child is as close to normal as possible. In addition, society benefits by the long-run less cost of special education for that individual. Studies show that taxpayers will spend billions of dollars during the life of handicapped persons in order to provide a minimum lifestyle. With the right kind of education and training these persons would become productive and independent members of society. Welfare has deep, negative effects upon the handicapped and his family.

[8] U.S. Code: P. 1479.

The right educational and therepeutical program will keep the handicapped out of institutions as well. Each year, billions of dollars are spent to maintain handicapped individuals in these less-than-human conditions.

Due to the fact that human tragedy is averted and tax-payers money is used as wisely as possible, an on-going emphasis upon pre-school education for the handicapped is justified. Unfortunately, many states express deep concern over the ability to finance these pre-school programs.

All too often the parents of handicapped children are reluctant to press for the identification, evaluation, and service for their children. They have been led to believe that their children cannot lead fulfilling lives. This is sad. Experience shows that handicapped children can often rise above their difficulty and lead meaningful lives. An encouraging note, however, is the fact that over the past few years these parents are beginning to realize that the Constitution of the United States of America provides for any necessary service to their children! Therefore, all over the country parents have been taking the educational systems to court in order to gain that which is to be provided their children.

In the years just prior to 1975 there were 36 court cases in the United States which declared the rights of handicapped children to an appropriate education. The states have made an effort to implement the decisions. Lack of money, however, has prevented full compliance to the decisions. Although some progress has been made, parents of the disabled children, and the children themselves, are too often told that there is not enough money available to provide them the free public education which the law requires, even though the courts have declared that insufficient funds may not be used as an excuse.[9] "As specifically stated by Judge Waddy in the Memorandum Opinion, Judgement and Decree (Mills v. Board of Education of the District of Columbia, 1972):

> 'The defendants are required by the Constitution of the United States, the District of Columbia Code and their own regulations to provide a publicly-supported education for these "exceptional" children. Their failure to fulfill this clear duty to include and retain these children in the public school system or otherwise provide them with publicly-supported education and their failure to afford them due process hearing and periodical review, cannot be excused by the claim that there are insufficient funds...the District of Columbia's interest in educating the excluded children must outweigh its interest in preserving its financial resources. If sufficient funds are not available to finance all of the services and programs that are needed and desirable in the system, then the available funds must be expended equitably in such a manner that no child is entirely excluded from a publicly-supported education consistent with his needs and ability to benefit therefrom. The inadequacies of the District of Columbia Public School System, whether occasioned by insufficient funding or administrative inefficiency, certainly cannot be permitted to bear more heavily on the "exceptionally" or handicapped child than on the normal child.'"

Recent statistical studies out of the Bureau of Education for the Handicapped reveal that there are over 8 million children (from birth to age 21) who are handicapped to the extent that they need the service of special education. Of this total, only 3.9 million are receiving an appropriate education; 2.5 million are receiving an inappropriate education; and 1.75 million are receiving no education! (See appendix I)

Public Law 94-142 is designed to serve all school-age handi-

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[9] U.S. Code, pp 1446 and 1447.

capped children with a free appropriate public education. This law has been called the strongest piece of civil rights legislation of recent times. In effect, it calls for the same consideration to be given a disabled child as would be given a normal child in the education experience. It mandates that, whenever appropriate, the handicapped child is to be educated right along side of the normal child.

Mainstreaming is the process of identifying, evaluating, and placing a handicapped student in a regular educational system. In the mid-seventies mainstreaming strongly caught the public's attention. The issue began to be aired over the media by public broadcasting with the MacNeil/Lehrer Report showing some mainstreaming in Massachusetts. A short time later the commercial network began to publicize this growing concern of parents and educators with Dan Rather and 60 Minutes looking at mainstreaming in some Michigan schools. Then, a regular prime-time show, The White Shadow, gave an episode to the issue of handicapped children in a regular school environment. The education of handicapped children was becoming an issue of national and even international concern. In fact, a British Government official called mainstreaming a "parent-guided revolution". Parent groups, public and private agencies advocating the rights of the handicapped, and professionals in the field of education presented a coalition of lobbying power that was to insure the passage of P.L. 94-142.[10] "For many reasons - including ignorance and embarrassment - families often fail to find help for a child with special needs." The National Library Service for the Blind and Physically Handicapped (write in care of Library of Congress

[10] "Books for Children Who Cannot See the Printed Page." by Margaret Bush, in the School Library Journal, April 1980, pp.28-31.

Washington, D.C., 20542) provides free informational packets.

In the realm of education for the handicapped, librarians should join with teachers in providing and supporting reading skills for children. The National Library Service (NLS) provides a braille and talking book program for the visually impaired. Congress annually appropriates funds so that libraries can purchase books and play back equipment. These funds are also earmarked to help train volunteers in the use, maintenance, and repair of this equipment, as well as the transcription of braille, and narration.

Parents, guardians, teachers, and librarians of handicapped children can apply for braille or talking book services through the appropriate regional library. The catalog Library Resources for the Blind and Physically Handicapped is provided free of charge by NLS. Children who are visually impaired or who have physical difficulties that prevent the physical handling of books may receive, free of charge, all reading materials, play-back equipment, and library services.

The NLS has on shelf hundred's of children's books in braille, print/braille cassette, and disc styles. Also in stock are children's magazines and music instruction tests.[11] "The basic selection philosophy is that handicapped children are entitled to the same range of reading materials enjoyed by non-handicapped friends and classmates, so book titles selected for production each year include picture books and all genres of fiction and non-fiction at varying levels of interest and difficulty for children from preschool through junior high-school

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[11] Bush, p. 28.

ages." Utmost concern to the NLS is that these books are as close as possible in story outline and content to the original works. The books published by NLS are not shortened, dramatized, or with music backgrounds. Application to use these materials must be signed by a professional in medicine, social work, or education. The services provided by NLS may be used on a temporary basis or for life. NLS seeks to meet the reading needs of a handicapped at the point of need. The handicapped are encouraged to use these books and materials at home. Two magazines, Braille Book Review and Talking Book Topics, are issued by NLS bimonthly and describes the current reading materials available. Material ordered is sent by mail and returned by mail to the library. There is no charge (including postage) whatsoever to the user.[12] As more children with special needs are being taught in regular classrooms, teachers often find that the wide selection of books provides handicapped children with opportunities to read the same books as sighted classmates. Nonfiction titles can also be used to augment classroom teaching on many subjects." As can be seen, the NLS services are as thorough and complete as its budget allows.

There are, however, due to the high cost of production, many thousands of titles which NLS cannot reproduce for the visually impaired or blind student. Thus, teachers and parents utilizing the service initially are often disappointed to realize that they cannot obtain all the reading materials wanted through this service. Many times, however, NLS acts as a referral service, helping these people to find the desired title.

[12] Bush, p. 30.

NLS provides recreational reading and trade-book studies for the handicapped. The department of Health, Education, and Welfare has been charged with the responsibility to provide classroom textbooks for use in the education of the handicapped. States may purchase these texts from American Printing House for the Blind. "Textbooks are also recorded upon request and free of charge for individual needs by Recording for the Blind, a volunteer organization based in New York."[13]

Mandates of P.L. 94-142

The Education for All Handicapped Children Act mandates that the education may take place in school, at the child's home, or in health care facilities, but that it must be a free appropriate public education. Further, handicapped children are to be educated with normal children, as far as possible. The use of segregated schooling is to take place only when the handicap is so severe that the child cannot be satisfactorily educated in a normal classroom even with the use of special equipment and education.

The Federal Congress has defined free appropriate public education[14] as "special education and related services provided at public expense which shall include an appropriate preschool, elementary, or secondary school education in the applicable State and is provided in accordance with an Individual Education Program."

P.L. 94-142 directs the Commissioner of Education to encourage and motivate research and development of supplementary educational aids for the handicapped in the areas of telecommunication and sensory

[13] Bush, p. 30.
[14] U.S. Code: P. 1434.

devices. It is believed that such R and D will enable the handicapped to better utilize the public media.

Congress gave special emphasis to the fact that the parents of the handicapped were not to pay for the education of their children. The fiscal responsibilities belong to state and local educational systems. The Act also strongly encouraged the use of existing programs, in both the public and private sectors, for purposes of educating the disabled. The local and state agencies can thereby stretch the dollars allocated to them for the education of the handicapped.

Scope and Intent of the Individual Education Program

The Individual Education Program (IEP) is the expression of both long and short range goals for the education of the individual handicapped child. Each handicapped child, by law, must have a written IEP. This plan (IEP) must include identification, evaluation, and placement of the child in the educational setting. The IEP is arrived at through the combined efforts of parents, teachers, educators, and, where appropriate, the child himself. There can be no implementation of an IEP without the approval of the parents of the handicapped child! The IEP is to include a description of the child's present educational level; short-range educational objectives; and, a step-by-step explanation as to how these objectives will be achieved. (See appendix II, III)

The IEP is also composed of "specific educational services[15] to be provided to the child, the extent to which the child will participate in the regular educational program, and the projected date for

[15] U.S. Code: P. 1483.

initiation and anticipated duration of such services." This law authorizes the Commissioner of Education to employ twenty experts to supervise this nationwide IEP writing.

Implementation of P. L. 94-142

These twenty experts also have responsibility to supervise state fiscal and educational plans for the implementation of the law, as well as conducting data collection and evaluation for all fifty states. The heavy paper-work flow can become a source of bureaucratic bottleneck. This is a potential annual implementation problem.

As state educational programs for handicapped are under-going a review, evaluation, and application process more information is being gathered as to the needs of the handicapped. Blind persons who have entered the professions (such as scientists and educators) have much to say to us regarding the education of the disabled. Many of these professionals are concerned that education for the handicapped be fair, proper, and flexible. They feel that an effective, early education will lay a good foundation for the handicapped child to be comfortable in an integrated school setting. They further see this school integration to be essential to the effective teaching of human and social values to handicapped and normal children alike. Residential schools for the handicapped prevent early socialization for the disabled child and may make more difficult the later integration process.

These experts advocate that the handicapped child pass or fail a particular subject according to the same criteria as normal children. there should be no additional or different criteria for the disabled child. The handicapped must compete with the normal on equal terms with common sense providing the guidelines.

In addition, P.L. 94-142 provides that any necessary special education (i.e. tutoring sessions with a teacher specializing in the child's area of need, and with the use of instructional materials) along with necessary services such as transportation, psychological counseling, disabled therapy, and career counseling be provided.

We have pointed out many reasons for a handicapped child to receive an appropriate public education in a normal school. Some other things need to be said about the undesirability for a child to needlessly attend a special school. These schools pinpoint and exaggerate the differences between handicapped and normal children. Their study programs and educational staff tend to be lesser qualified than the normal school counterpart for traditional education. They are often a far distance from the child's home, thus compounding the problems and difficulties of the handicapped and their families.

Experts in the field of education testify that mainstreaming works best when the handicapped child, the parents, the teachers, and the school administrative staff are committed to making it work.

There are other problems the handicapped child and his family must face and overcome in the formal educational process in the United States. The classification of handicapped children presents one such problem. The Senate Committee which researched the handicapped issue and wrote up the bill which became P.L. 94-142 had this to say:[16] "The Committee is deeply concerned about practices and procedures which result in classifying children as having handicapping conditions when, in fact, they do not have such conditions. These practices have been

[16] U.S.Code: P. 1450.

brought to the Committee's attention at hearings and in recently published studies (notably the report of the Children's Defense Fund, entitled, Children Out of School in America). At least three major issues are of concern with respect to problems of indentification and classification: (1) the misuse of appropriate identification and classification data within the educational process itself; (2) discriminatory treatment as the result of the identification of a handicapping condition; and (3) misuse of identification procedures or methods which results in erroneous classification of a child as having a handicapping condition."

There are recorded cases of mis-treatment in all of the above instances. The child is the primary sufferer in these cases. Each of these situations are unique, however, and must be dealt with on an individual basis. It is of the utmost importance that correct identification of the handicapped child take place so that an appropriate public education may occur. The disabled child must receive the proper services for an optimal education experience. Without a correct identification and classification of a given handicapped child any ensuing educational program would be inadequate and inappropriate.

Another problem facing the disabled child is the label of 'handicapped'. If special care and consideration is not taken the child will receive a label that says to other children that this one is 'different' and therefore to be set apart. The Senate Committee addressed this problem as well.[17] "Central to this issue is the discriminatory treatment which results from the identification of handicapping

[17] U.S. Code: P. 1451.

conditions. Disabled witnesses testifying before the Committee made this point absolutely clear. They testified to the fact that they recognized the need for the identification and labelling of their handicapping conditions, if that identification and label meant that appropriate educational services would be forthcoming. Speaking to the problems of labelling children as 'handicapped', they pointed out that children with visible handicaps carry with them, throughout their lives, a condition which cannot be disguised and which, in the eyes of some people, may set them apart. As they also pointed out, such classification and identification has too often meant separation, discriminatory treatment, and a reason for failing to provide any services at all. the problem is not the classification itself, since that classification is a necessary tool for designing appropriate instruction. The problem is the stigma that such classification carries with it, and the resulting discriminatory treatment and exclusion which occurs. It is this discriminatory treatment and exclusion which court cases, State and Federal laws are designed to remedy." Unfortunately, the courts of the land cannot change people's attitudes. It belongs to the sociologist, educator, parent, and religious leader to teach the inherent value and dignity of all human life.

Implementation Difficulties and Problems

To pass a law does not automatically mean application, acceptance, and compliance. It is a long road from the passage and signing of a bill into law and the implementation of that law. We, finally, want to consider some of these problems.

In the first place, a new law must be interpreted by (1) the persons responsible for its application, (2) the people who are directly and indirectly benefitted by the law, and (3) often the courts of our land. Many times the interpretation of the law is not what the legislators meant when they brought it to its final form. Secondly, the application of the law is not what the bureaucrats, business leaders, and other powerful people interpreted the law to mean.

Thirdly, the assigning of fiscal responsibilities for the implementation of a law can become a complex process. Such decisions must be made as: Which departments of federal, state and local governments are responsible to implement the law? Which parts of the law? How much of the funding do they provide? Is the money available now for part or all of the implementation of a bill? From where is the money coming? What kind of an accountability system will be instituted? Who is accountable for what and to whom? There are powerful forces at work, in the realms of business, legal systems, and coalitions for advocacy attempting to direct the interpretation, application, and financing of a law. Let us return to our case study and consider some implementation difficulties facing Public Law 94-142.

The Educational Amendments of 1974 required certain specific and in-depth reports from the states to the Commissioner of Education. These amendments required that by August 21, 1976, states would have filed with the Commissioner's office data regarding[18] "policies and procedures to ensure that all handicapped children within the State would be identified, located, and evaluated; that a goal of providing full

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[18] U.S. Code, p. 1427.

educational opportunities would be established, including a timetable for delivery of full services to all handicapped children; and that a description of the facilities, personnel, and services necessary to meet such a goal be included...(the law requires) that a State, in order to be eligible for funding, must have a 'right to education' policy for all handicapped children, aged 3 to 18 will have available to them by September 1, 1978, a free apropriate public education, and that all handicapped children aged 3 to 21 will have available to them by September 1, 1980 a free appropriate public education."

P.L. 94-142 goes on to require that states submit yearly applications for funds. This application is to include: explanations of the state educational plan for the handicapped children; statement of disbursement of funds to state and local education agencies; explanation of how the state is using Federal funds available under other laws and from different departments to supplement the cost of their education plan; descriptions of the special training program for teacher's involved with the education of handicapped children; and, a timetable for the implementation of all these requirements. There are many difficulties with these procedures and programs.

One of the most noticeable problems which has arisen is the tremendous volume of paperwork with the accompanying commitment of time, staff, and other resources to the accomplishment of these major requirements.

Another problem regarding the implementation of P.L. 94-142 is the fact that legislative efforts surpass current abilities in the areas of funding, professional technique and technology. It is required that each student have an individual evaluation that is not discriminatory. There are technical difficulties with the designing, administering and evaluating of these tests.

The need to refine the IEP process is a third problem. Many times parents are intimidated by the technical language and professionalism of the education system when they sit down with the educators to identify and evaluate the child's needs and to map out a short-range goal and long-range objective plan for the education of their handicapped child. Too often, the parents become a rubber stamp in this process instead of initiators and advocators for the disabled child. There is a great deal of rhetoric in general education today about the involvement of parents in the education process. Refinement of the IEP process will be a catalyst that pushes and hurries parental involvement into reality for all parents. The parents of the handicapped must be trained to talk the language and understand the expertise affecting their children.

Fourthly, P.L. 94-142 faces an uphill fight for appropriations from Congress. At this point, the Federal govenment is supposed to be paying 40% of the cost for the education of a handicapped child. It is currently providing less than 20% for an individual disabled child's education.

The Education for All Handicapped Children Act mandated that there must be one sole state agency responsible for the implementation of P.L. 94-142. While a wise decision, it has given rise to a fifth problem. Often, there have been other agencies traditionally responsible for the care and education of the handicapped children within a state. There is now much jealousy, rivalry, and fighting for 'bureaucratic turf' among many public and private agencies within most states, In addition, parents and students still find themselves shunted from agency to agency as they try to pinpoint specific responsibilties.

A sixth problem is that of child identification within the states. Many times the states are above or below the best estimates for the number handicapped. State fiscal plans and applications submitted to the Fedearl Government are therefore an unrealistic picture of the actual financial needs for the education of the disabled children in that state.

A seventh, and related problem is that many non-English speaking children, children on Indian Reservations (whose education is the responsibility of the Department of the Interior), and children in urban areas are not being reached.

Lastly, if states do not want to comply with the guidelines of the Education for All Handicapped Children Act they do not have to do so. They do, however, forfeit any funds available for them under this Act. Currently, New Mexico is the only state not participating. However, section 504 of the Rehabilitation Act outlaws discrimination for states receiving <u>any</u> Federal funds, so even though they do not follow the guidelines, the children's rights are still protected.

CONCLUSION

While the intent of P.L. 94-142 is that the state educational agency be solely accountable for implementation of the law, this same state agency ought not be the sole provider of services to the handicapped, especially with regard to preschool children. The state educational agency should coordinate the many existing private and public programs for preschool children with the agency's own educational programs. It must be remembered, however, that any services provided to the disabled child must meet the requirements of P. L. 94-142. Further, it must be remembered, that it is necessary there be parental involvement in the planning and implementation of an educational program for a handicapped child.

Experience shows that if there is no sole agency accountable for the implementation of a law that allegations are brought between various agencies charging failure to comply with and/or fulfill responsibilities.

Additionally, if final responsibilities are divided between agencies, parents are frustrated with:

(1) attempts to discover which agency is accountable for specific areas,

(2) the necessity to learn a particular agency's terminology and system,

(3) the need to explain the same things time and again to authorities in different agencies.

(4) being sent from agency to agency in an attempt to place them where their particular need can be funded.

For these and other reasons heretofore mentioned, it is good that P. L. 94-142 assigns sole responsibility to the state education agency.

[19] "Court action and State laws throughout the Nation have made clear that the right to education of handicapped children is a present right, one which is to be implemented immediately."

One last word to the recipients of the services of a law: know your rights under the law and who is responsible for the implementation of the law.

You have heard it said many times, "ignorance of the law is no excuse", and it is true. It is also true that "a little learning is a dangerous thing". Be informed, be aware, and secure sound expert advice for your particular need.

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[19] U.S. Code 1435

PERSONAL CASE STUDY

Our daughter, Erin Joy, was diagnosed with cancer in her right eye in August, 1977. The subsequent enucleation of her eye did not, however, end Erin Joy's (and our family's) fight against cancer. In February of 1978, the church in which we serve (both Lynda and I are ordained protestant ministers within The Salvation Army church) transferred us to St. Louis, Missouri, where we assumed the responsibility of pastoring a new church. Erin Joy was a year old. One of the first things we did was to contact the ophthalmologist to whom we were referred for an eye examination for Erin. Our new doctor could not examine Erin's eye during the office visit because she fought too hard against it. Circumstances would prove the need for Erin Joy to be a fighter.

The doctor suggested that an evaluation of Erin's left eye and right eye socket be done under anesthesia. We agreed. An appointment was made for March after the doctor returned from vaction.

Neither Lynda nor I will ever forget the look on the doctor's face as he summoned us from the waiting room after the examination. His face was clouded and he seemed to be very burdened. With leadened hearts we stepped into the hallway to face what would come.

"I'm so sorry," the doctor said. "There are some tumors on the retina of Erin's left eye. I'm just so sorry."

"What does this mean?" we asked.

"I'm afraid we must remove the eye," he replied. "We have to consider the spread of the metastasis."

"Dear God," we prayed, "we need Your strength. Help us to understand what's happening to our precious little girl."

"You're talking about total blindness, then," I said.

It felt as if my gut was being wrenched apart. Our doctor introduced the man standing with him as another specialist whom he had asked to step into the operating room for a second opinion about our daughter's eye. He confirmed our doctor's diagnosis and suggested surgery.

I asked if there were any alternatives available to us. The second doctor brusquely told us that there were none. He reiterated that the eye must be removed, and said the appointment should be made for the next day. I turned from him to our own doctor and asked the most important question that can be asked of a doctor in such a difficult circumstance.

"Doctor, if Erin Joy were your daughter, what would you do?"

He thought for just a moment and then he told us he would take her to one of two specialist he knew. He went on to explain that he was quite sure they would be unable to do anything but that each was one of the top men in the world in the treatment of retinoblastoma.

At this point the second doctor chose to break in with this observation: 'Such a trip would be a waste of our time and money. Our daughter's tumors were too far advanced for any successful treatment and we might as well accept the fact our daughter would be blind'.

I ignored him.

"When would you take your daughter to see this specialist you know?", I asked our doctor. "I'd have her on the plane tomorrow", he responded.

We told the doctor we wanted some time to talk alone. Time was of the essence. Decisions had to be made. The doctor instructed the nursing staff to come and get him when we returned.

Lynda and I were numb in mind and soul as we found a quiet hospital patio where we could be alone and talk. We found consolation in the one fact we had clung to since we ourselves were children. We were God's children. He loved us. Erin belonged to God before she belonged to us, and as much as we loved her, God loved her more. He had a perfect plan for her life and He wanted us to trust Him. And so we would.

We decided to take Erin to see the specialist. We felt that even if they could not treat the cancer, we would be able to say to our blind daughter when she reached an age of understanding, we did everything we could to save your vision. We sought out the best men in the world in this field. We could say that we did our best.

Four days later we were on our way to Wills Eye Hospital in Philadelphia to see Dr. Jerry Shields, Retinal Oncologist. (The other specialist was in New York City, but was out of the country when we called.)

We had driven to Michigan to leave our son, Greg, with my parents. The doctor said we would probably be gone two or three days. He also suggested that in the event Dr. Shields was unable to treat the eye that he just remove it while she was under the anesthesia.

Those two or three days expanded into almost seven weeks. After the first few nights in an expensive hotel near the hospital, we moved into Ronald McDonald House. How thankful we were for a convenient (six blocks from the hospital), inexpensive lodging ($5 a night), where we had our own private sleeping room and shared living room, kitchen, and bath facilities. There were other families there whose children were facing terminal illnesses. (We are very excited about the Ronald McDonald House which will be opening in St. Louis in mid-March, 1982.) This facility is provided in cooperation with the McDonald Corporation and the professional football teams in each city they are located. Parents and children can stay together as they face the treatment schedules devised for them by their doctors. It is a refuge from both the eyes and ears and financial pressures of public hotels and accomodations.

What was to follow for our family and Erin Joy is not an easy story to tell. We share it only because it offers hope and reassurance to others who must travel the rough roads to recover from cancer. For Erin Joy this began with 26 beam radiation treatments. Before each session she had to be sedated with an injection, after which we walked her for an hour to let the medicine take effect. There was one session each day, Monday through Friday, for almost six weeks.

The day following the last radiation treatment Erin went to Children's Hospital in Philadelphia, for an intense physical including three spinal taps. Later that afternoon, she began the first of 20 chemotheraphy sessions which would last for over a year and a half.

In the midst of all this time, Erin underwent three traumatic cryotherapy surgeries which "froze" the tumors in her eye and eventually led to a completely deadened stage for each tumor.

All of the trauma and difficulty and financial strain which our family has gone through over these past three years was a fight to save Erin's vision. After all Erin had gone through, all the roller-coaster emotions such an experience brings, from the highest of hopes to the deepest of despairs, in August of 1980 the cataract which brought the discovery of cancer had grown to such proportions that Erin was totally blind. Dear God, how it hurt to think back on all the struggle and pain of the past three years. But again, our faith continued to sustain us. Romans 8:28, "When we love God, He works all things for our good." We believed that what has happened to Erin Joy and to our family is for our eternal good. Not that God planned for it to happen, but when it did happen, He used it for His good and ours. We do not believe God plans pain and suffering for His children. It is a part of life. We all experience suffering in one degree or another. We do know that God cares for us. I Peter 5:7 tells us that "our care is a constant concern to Him".

Our Lord and Saviour Jesus Christ told a parable during His days on earth. He said in effect, that God cares for and loves even the smallest of sparrows and sees when it falls from its nest. God's love and care surrounds us. He is keeping His eye upon our little sparrow, Erin Joy.

Although we do not know what the future holds, we know God holds us, and the future in His Hands!

EPILOGUE

On December 11, 1980, another doctor in Philadelphia, specializing in the extraction of cataracts from children's eyes, removed the cataract that prevented Erin Joy from seeing. The doctor was very optimistic about the results saying he removed as much of the lens as he wanted. So we returned to St. Louis to wait and see what would happen.

On January 22, 1981, our St. Louis ophthalmologist inserted a contact lens on Erin's eye. Because she had never seen, he made an educated guess at the prescription of the lens. After dinner that same evening, Erin Joy called her mother into the family room in a very excited voice. There she spoke the five most beautiful words we have heard in a long time, "Mom, I see Big Bird!"

And it was true. She did see Big Bird. The next day she saw her shadow and a waitress in a restaurant. And there were questions, questions, questions!!! And how we praised God for the questions!.

It is still a long road we must travel for Erin to learn to utilize her newly-given vision. But what joy is in our hearts as we step out.

The tumors are still in regression. The doctors tell us that with every six months the chance of reactivation grows less.

Medically, we look forward to our semi-annual trips to Philadelphia becoming annual events. And by the time she is a teenager, bi-annual events.

Educationally, my wife and I are prepared to do whatever it takes to have an active, viable part in determining Erin Joy's Individual Education Plan. We are thankful for P. L. 94-142 which not only publicizes the need for education of handicapped children to parents and educators, but also defines and protects our child's constitutional right to a mainstream free appropriate public education. For all of this we are thankful--to our community, congress, and country.

But mostly we are thankful for the very precious gift, loaned to us by God, who has brought us closer to our God and our family, and a greater sense of purpose in living. Our Erin Joy has surmounted more obstacles in her three years than most people do in a lifetime. She is a very happy, lively little girl who prays every night for God to bless the people who are sick. She knows they need His help, because she's been there and back again!

	1974–75 served (projected)	1974–75 unserved	Total handicapped children, served and unserved	Percent served	Percent unserved
Total age 0 to 19	3,947,000	3,939,000	7,886,000	50	50
Total age 6 to 19	3,687,000	3,062,000	6,699,000	55	45
Total age 0 to 5	260,000	927,000	1,187,000	22	78
Speech impaired	1,850,000	443,000	2,293,000	81	19
Mentally retarded	1,250,000	257,000	1,507,000	83	17
Learning disabilities	235,000	1,731,000	1,966,000	12	88
Emotionally disturbed	230,000	1,080,000	1,310,000	18	82
Orthopedically and other health impaired	235,000	93,000	328,000	72	28
Deaf	35,000	14,000	49,000	71	29
Hard of hearing	60,000	268,000	328,000	18	82
Visually handicapped	39,000	27,000	66,000	59	41
Deaf-blind and other multi-handicapped	13,000	27,000	40,000	33	67

Source: Bureau of Education for the Handicapped, U.S. Office of Education (Note that the term "orthopedically impaired" is used in place of "crippled" to conform with legislative change made by S. 6)

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TEACHERS MIGHT GIVE PARENTS A LIST OF QUESTIONS TO BE THINKING ABOUT PRIOR TO THE CONFERENCE SUCH AS:

What skills would you most like your child to learn?

Are there concerns about your child's functioning at home that could be addressed by work at school?

What aspects of your child's behavior do you believe need to be improved?

What do you believe to be your child's strengths and weaknesses?

What methods have you found to be effective in rewarding and punishing your child?

To what extent does your child interact with children in the neighborhood?

What are your feelings about providing opportunities for your child to interact with non-handicapped children?

By providing a list of these questions ahead of time, parents will have an opportunity to think about the kind of comments they would like to make at the IEP conference. Teachers might also want to schedule the IEP conferences with individual parents at the group meeting and to assist in working out any logistical problems such as transportation.

From Turnbull, Ann P. Parent-professional interactions. In Martha Snell (Ed.), Curriculum for the moderately and severely retarded. Columbus, Ohio: Charles E. Merrill Publishing Co., in press.

P.L. 94-142, The Education For All Handicapped Children Act, guarantees a free, appropriate, public education for all children regardless of any handicapping condition.

All handicapped children are required to have an IEP (Individualized Education Program). This is defined as a written statement for a handicapped child that is developed and implemented in accordance with P.L. 94-142. Individualized means that the educational needs of a single child rather than a class or group of children will be looked at. Special education is specifically designed instruction which meets a child's unique needs. Special education includes classroom instruction, physical education, homebound instruction, and instruction in hospitals and institutions, as well as vocational education. Related services are any additional services, INCLUDING TRANSPORTATION, which are necessary for the child to benefit from the special education. Program means a written statement of what will actually be provided to the child during the school year. A program is specific and detailed--not just an outline or plan.

An IEP must include:

1. A specific statement of the child's present level of educational functioning.

   EXAMPLES:

   (Too general -- John's present functioning is about kindergarten level.)

   IEP should state -- John's present functioning: He can count to 10; recognize written numbers to 5. He can recognize his printed name.

   (Too general -- David is now functioning on a low third grade level.)

   IEP should state -- David can read and comprehend on a third grade level. He can spell third grade level words with 60% accuracy. He can compute simple math such as 6+2=, 9-3=.

2. A specific statement of annual goals, including short term instructional objectives.

   EXAMPLES:

   (Too general -- John's annual goal is to increase number concepts this school year.)

IEP should state -- John's annual goals would be to increase overall academic ability, to increase number concepts, etc. His short term objectives would be that by the third quarter of the '79 school year he will recognize written numbers to 10; identify letters of his name.

(Too general -- David's annual goal is to increase reading and spelling ability.)

IEP should state -- David's annual goals would be to increase reading comprehension and to increase written vocabulary. His short term objectives would be by the semester he will answer written comprehension questions with 50% accuracy and by the end of the '79 school year he will spell third grade words with 75% accuracy.

3. A statement of specific educational and related services to be provided to the child and the extent to which he will be able to participate in regular classes and activities.

EXAMPLES:

(Too general -- John will receive speech therapy.)

IEP should state -- John will receive speech therapy three hours per week implemented by the speech clinician using the Peabody Language Kit Level P, Language Master (this should be specific books and equipment).

(Too general -- David will receive remedial reading and participate in regular classes.)

IEP should state -- David will receive individualized remedial reading five days a week for 30 minutes. He will participate in regular classes of Physical Education, Art, Music, Science, and Language.

4. The projected dates for beginning the services and how long the services will last.

EXAMPLES:

(Too general -- John's IEP will start in September and continue through the school year.)

IEP should state -- John's IEP will be implemented 9/79. Progress will be noted 1/80 and 4/80, reevaluation in 5/80.

(Too general -- Implementation of David's IEP will begin 12/79 and continue until 5/80.)

IEP should state -- David's IEP will be implemented in 12/79. Progress will be noted 3/80 and new goals established when David spells third grade words with 75% accuracy. David will continue daily 30 minute sessions of individualized reading until 5/80.

5. Concrete ways of evaluating, at least yearly, how well short term objectives are being met.

EXAMPLES:

(Too general -- John will know numbers 1 through 10.)

IEP should state -- John will identify number flash cards up to 10 and will show increased mental age on Peabody Language Test.

(Too general -- David will show improved reading skills.)

IEP should state -- David will show improved reading skills, spelling skills, and comprehension by scoring at least a 3.5 grade level on the Durrell Listening-Reading Test.

When writing and reviewing objectives, remember that objectives are SMART: Specific, Measurable, Acceptable, Realistic, and Time specific. You not only have the right to participate in the development of your child's IEP, you also have the responsibility to do so. You, as parents, are the key part of your child's education. It is your responsibility to carry your part of the program. Education does not stop when your child leaves school. Work with your child's teachers to see that the education given your child is the best it can be. Bear in mind that an IEP must be reviewed at least once each year and revised if necessary.

For additional information, contact:

Missouri Developmental Disabilities Protection and
Advocacy Services, Inc.
420A Brooks Street
Jefferson City, Missouri 65101

Telephone ~~314/636-811~~3

1-800-392-8667

Parents or Guardians:

If you disagree with the school's decision regarding your child's Individual Placement Program, YOU HAVE THE RIGHT TO AN IMPARTIAL DUE PROCESS HEARING.

A due process hearing is an exhausting process. Before starting this process try to settle your differences through every other means--by being as persuasive as possible in meetings with teachers, principal, and special education administrators. If these attempts are not successful, you should know the following important points about due process procedures:

1. You must request a due process hearing in writing.
2. The school district must provide you with reasonable notice of a hearing.
3. At the hearing, you have --
   a. the right to be accompanied by counsel, may present your own case, or make use of advocates (e.g., parents skilled in challenging school action);
   b. the right to present evidence, ask questions, and compel the attendance of any person who can give relevant information;
   c. the right to obtain a written or electronic record of the hearing; and
   d. the right to obtain written findings of facts and decisions.
4. The hearing must be conducted by an impartial hearing officer who is not employed by the school district for any purpose other than to serve as a hearing officer.
5. If you are dissatisfied with the result of the due process hearing you may appeal to the State Department of Education.
6. All hearings must be at a time and place convenient to you and your child.
7. Hearings and decisions should be rendered within 45 days of the written request for a hearing.
8. Your child may remain in his present educational placement during the course of any administrative or judicial discussions regarding a complaint.
9. If your complaint involves application for initial admission to public school, your child must be placed in a public school program until a hearing determines otherwise.

The staff of Missouri Developmental Disabilities Protection and Advocacy Services can help you within the limits of our resources. You may contact us at 420A Brooks Street, Jefferson City, Missouri 65101 or call 314/636-8113.

A handbook entitled "94-142 and 504: Numbers that Add Up to Educational Rights for Handicapped Children" can be obtained free of charge by writing: Children's Defense Fund, 1520 New Hampshire Ave., N.W., Washington, DC 20036.

PARENT AND CHILD RIGHTS IN P.L. 94-142

As a parent of a child who has been identified as having special needs, the following rights are provided through federal legislation (P.L. 94-142):

1. A free appropriate public education with necessary related services to meet your child's needs (i.e., speech therapy, physical therapy, counseling, and transportation) must be provided by your local school system.

2. Your child must be placed in an educational program as close to children who have not been identified as having special needs, in consideration of the appropriateness of the program for your child. This means, for example, that your child may not be removed from his regular class placement to be put in a special class attended only by children with special needs unless you and the school personnel believe that the special class would be the best placement for him.

3. Your child may not receive an initial evaluation in order for placement in a special education program unless you are previously informed and voluntarily give your consent. If you make the decision to give your consent, you may withdraw it at any time.

4. You are entitled to receive an explanation of all evaluation results and explanation of any action proposed or rejected in regard to evaluation results.

5. You have the right to request an independent evaluation (conducted by someone outside of the school) and have the results considered in discussions regarding the school placement of your child.

6. You may inspect all educational records and request explanation of information contained in the record. You may also request that information be amended if you do not agree with it.

7. The privacy of all school records must be maintained. You may request copies of your child's records. Further, you may obtain information from the chairperson of the special services committee concerning the particular individuals who are allowed to see your child's records.

8. You have the right to request an objective hearing (due process hearing) at any time when you disagree with the proposed procedures for evaluation and/or placement of your child. At the hearing you may have counsel, present evidence, cross-examine witnesses, and obtain written findings of the proceedings. If you are deaf or normally communicate in a language other than English, the hearing must be conducted so that all communication is completely understandable to you.

From: Turnbull, Ann P., Strickland, Bonnie B., & Brantley, John C. Developing and implementing individualized educational programs. Columbus, Ohio: Charles E. Merrill Publishing Company, in press.

AGENCIES WHO HELP THE VISUALLY IMPAIRED

Agency	Eligibility Requirements	Cost	Services
Bureau for the blind Prevention of blindness, 619 E. Capitol St.,Jefferson City, Missouri 65101	Blind or visually handicapped	None	If you qualify there is financial help for medical expenses, glasses, prothesis, etc., rehabilitation services, counseling.
Delta Gamma Foundation,9313 Manchester Road, St. Louis, Missouri 63122	Visually handicapped, Multi-handicapped, including vision.	None	Home visits by professional worker, works to stimulate learning abilities of child, counsels parents, type of nursery school available on limited basis.
National Association for Visually Handicapped,305 E. 24th Street, New York City, N. Y. 10010	None	None	A clearinghouse for all public and private services available to the partially seeing.
Knights Templar (Masonic) 14 East Jackson Blvd., Suite 1700 Chicago, Ill. 60604	Individual	None	Provides financial help for eye surgery Examinations, etc., on an individual basis.
Lions Club International 300 22nd Street Oak Brook, Ill. 60570	Individual	None	Gives aid to the blind and visually impaired, glasses, surgery, prosthesis, etc.,on an individual basis.

You must be aware there are numerous agencies who might be able to help you and your particular need. We suggest going to the reference section of your public library and asking for the Directory of Agencies Serving the Visually Handicapped, or the Encyclopedia of Associations. (See Master Bibliography for details.)

CHRONOLOGIAL ORDER OF EVENTS IN ERIN JOY'S LIFE AND STRUGGLE FOR VISION

March 7, 1977	Born in Grand Haven, Michigan.
March 12, 1977	Doctor diagnosed congenital cataracts.
August 2, 1977	Doctor discovers retinoblastoma (cancer of the retina of the eye) during routine check-up, Muskegon, Michigan.
August 3, 1977	Retinoblastoma confirmed by specialist in Grand Rapids, Michigan.
August 4, 1977	Enucleation (removal) of the affected eye in Muskegon, Michigan.
September, 1977	Prosthetic eye put into Erin's socket.
January 29, 1978	Family moves to St. Louis, Missouri
March 30, 1978	Examine under anesthesia reveals 5 tumors on Erin's other eye.
April 4, 1978	Doctor in Philadelphia prescribes radiation, cryotheraphy, and chemotherapy.
April 5 - May 10, 1978	Treatments at University of Pennsylvania Hospital and Children's Hospital of Philadelphia.
May 10, 1978 - July, 1979	Chemotheraphy treatments at St. Louis Children's Hospital.
June 1980	Due to the growth of the cataract, Erin is totally blind.
December 11, 1980	Surgery for removal of cataract performed in Philadelphia.
January 22, 1981	Contact lens inserted in St. Louis. Erin Joy sees Big Bird!
January 23, 1981 - and each day since	Erin Joy is discovering new worlds and glorious wonders!

MASTER BIBLIOGRAPHY

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