

MEDICALLY FRAGILE CHILDREN

**A Comparison of Three States' Methods
for Addressing Their Educational Needs**

by

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An Applied Research Project (Political Science 5397) Submitted to the
Department of Political Science of
Southwest Texas State University
in Partial Fulfillment
for the Requirements of the Degree of

MASTERS OF PUBLIC ADMINISTRATION

Spring 1995

Faculty Approval:

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Chapter I

Introduction and Statement of Purpose

Throughout history man has had difficulty dealing with people who are different.

James J. Cremins, Ph.D.
Legal and Political Issues in Special Education
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People Who Are Different

Humankind has always had difficulty with people who were different, whether those differences be because of race, color, creed, or age. Those difficulties are probably most pronounced when dealing with handicapped members of society. In Roman times, the handicapped were abandoned; in the Middle Ages, they were "abused and neglected (Cremins, 1983(A): 3). Today, society still grapples with defining the optimum role for its handicapped members.

Over the past 150 years or so, society has found ways to deal with such diversity. although progress has been slow. Germans first used the term "special education" in the early 1860s (Heiny, as stated in Cremins, 1983(A): 4). According to Cremins, use of this term embodied a growing concern for less-fortunate citizens. It also demonstrated man's responsibility to his handicapped brothers and sisters (Cremins, 1983(A): 4.). "For the first time, many of the parochial, exclusionary, and essentially arrogant reward systems that for centuries had been built into social institutions were directly challenged" (Gerry and Benton, 1985: 41).

What Are Medically Fragile Children?

According to the Institute for Quality Improvement in Long Term Health Care at Southwest Texas State University, "a medically fragile child is one who:

- a) ranges in age from birth through age 21
- b) has a serious, ongoing illness or a chronic condition that has lasted or is anticipated to last twelve or more months or has required at least one month of hospitalization, and which requires daily, ongoing medical treatments and monitoring by appropriately trained personnel which may include parents or other family members
- c) requires the routine use of a medical device or the use of assistive technology to compensate for the loss of usefulness of a body function needed to participate in activities of daily living
- d) lives with ongoing threat to his/her continued well being" (Institute for Quality in Long Term Health Care, August 1994: 3)

Thus, medically fragile children require "above normal" care in order to function in society. A medically fragile child might have a breathing tube that must be cleaned out several times daily or a feeding tube that must be properly maintained. These children are at the greatest risk of being placed in institutions, e.g., nursing homes or hospitals (Children in Nursing Homes Comprehensive Report, September 1994). Many of these children live in nursing homes because it is either too difficult for their parents to care for them at home, or because their parents have relinquished custody, making these children wards of the state.

Medically fragile children can be "invisible" to many people in today's society. Perhaps this is due to their placement in nursing homes and the size of the population. According to figures from the Texas Health and Human Services Commission, in 1992, medically fragile children in Texas numbered between 1,042 and 5,209, or between .02 percent and .1 percent

of the total population of children in Texas.' (See the figures titled "Universe of Children" and "Number and Profile of Medically Fragile and Severely Disabled Children" in Appendix B for further information.)

The plight of these children was brought to the attention of Texas residents through a series of articles called "The Lost Children" in the Austin American-Statesman. Denise Gamino, the author of this series, painted a fairly bleak picture of the life that many of these children live. The author introduced Leon, a six-year old boy who was a nursing home resident because of his severe disabilities. Leon missed most of the school year because paper work at the nursing home delayed delivery of his customized wheel chair. He missed a class field trip to a pumpkin patch because the nursing home had sent him to school with a nearly empty oxygen tank. On another day, Leon was too dirty to go to school because no one at the nursing home had given him a bath. On still another day, the nursing home failed to send Leon's feeding tube attachment, so Leon couldn't eat lunch.

Ms. Gamino's series re-emphasized the things that can go wrong when a nursing home is in charge of a school-aged child. According to the article, approximately 300 Texas children live in nursing homes, many of them with mental retardation or other disabilities. During the four months of research for this series of articles, it was found that many of these children receive questionable educational services. In addition to Leon's case, other examples of these questionable educational services include the following:

¹It is difficult to get an accurate count of the number of medically fragile children because of the varying definitions and because of the questionable accuracy of figures from nursing homes and other institutions.

- A 19-year old quadriplegic who also has mental retardation who receives only 30 minutes of instruction per day; according to the article, her guardian feels that she would benefit from three to four hours per day.
- If a child is asleep when the teacher or teacher's aide comes by, the teacher will either pass on by to the next student, or will sit next to the child's bed and do paper work.

This time is counted as "educational services" on the nursing home's contact sheet.

Many people feel that it is a waste of time, money, and effort to provide educational services for such severely handicapped children. Many feel that because these children will not be able to lead "normal" lives they should not have to be provided with educational services. However, all children with disabilities, no matter how severe, are entitled to a "free, appropriate public education" in the "least restrictive environment."

Research Purpose

The purpose of this applied research project is twofold. First, a framework/guidelines for an ideal policy for providing educational services to medically fragile children is developed and described. This framework is based on a review of Public Law 94-142, the Individuals with Disabilities Education Act (as amended); Section 504 of the Rehabilitation Act of 1973; issues relevant to the delivery of services for medically fragile children; recommendations for state policies, or actual recommendations for such policies; and relevant literature.

Second, the Michigan's policy for the provision of services to medically fragile children and Iowa and Texas' recommendations for such a policy is evaluated against this framework. Michigan and Iowa were chosen because the variances in funding for health and human services

as compared to Texas. Texas is a fiscally conservative state, while Michigan is fairly progressive; Iowa falls somewhere in the middle.

Chapter Summaries

This applied research project is organized in six chapters. Chapter 1 includes the Introduction. Chapter 2, "An Overview of Relevant Legislation for the Handicapped," discusses federal legislation relevant to this applied research project, Public Law 94-142 and Section 504 of the Rehabilitation Act of 1973. Chapter 3, "A Brief History of Legislation for the Handicapped," addresses the history of federal legislation for the handicapped. Chapter 4, "Research Methodology," reviews and justifies the two research methodologies chosen for this project, case study and document analysis. Chapter 5, "Analysis of Methods for Dealing with Medically Fragile Children," includes the case studies of the three states referenced above. The policies (or lack thereof) for each of the states will be outlined. Relevant background material regarding the development of the policies will also be presented. Chapter 6, "Summary and Concluding Remarks," concludes the applied research and gives the results of the comparison to the conceptual framework. Suggestions for improving individual state policies or recommendations will also be provided.

Chapter 2

An Overview of Relevant Legislation for the Handicapped

This literature review serves three purposes. First, legislation for the handicapped which is relevant to the topic of this applied research project, Public Law 94-142 and Section 504 of the Rehabilitation Act of 1973, is discussed. Second, two specific provisions contained within that legislation, "free, appropriate public education" and "least restrictive environment" are reviewed. Finally, the future of such legislation is assessed and the conceptual framework and basis for evaluating the individual state policies/recommendations for policies are presented.

Introduction

Federal legislation *has* been the single most significant incident in the total history of special education.

Reynolds and Rosen
"Special Education: Past, Present, and Future"
Educational Forum

Public Law 94-142 and Section 504 of the Rehabilitation Act of 1973 "are the primary enactments relied upon by those seeking to protect and enforce handicapped children's rights" (Hyatt, 1981: 2). This chapter addresses issues relevant to each piece of legislation and focuses on two critical provisions, "free, appropriate public education" and "least restrictive environment."

Public Law 94-142

Public Law 94-142, more commonly known as the Individuals With Disabilities Education Act (IDEA), was signed into law in November 1975. It guaranteed a handicapped child the right to a "free, appropriate public education" in the "least restrictive environment" (Cremins 1983(A): 14; Weintraub and Ballard, 1982: 4).

The role of the Federal Government became more substantial by the passage of Public Law 94-142 (Thomas, 1985 (A): 13); many states resisted the Federal Government's involvement in what was often viewed as a state and local function -- education. Congress got around this by mandating that education is a right for all children. The Congress and the Supreme Court still seem to be at odds with the "state control issue" (Lantzy, 1992: 3-4).

Public Law 94-142² is the statute that funds special education programs (Cremins, 1983(B): 23; Guernsey and Klare, 1993:6). Public Law 94-142 "streamlined" the original funding provisions of Public Law 91-230

- 1) to focus the distribution of *funds* to the *states* based on an incentive *formula* relative to the actual delivery of services by a time certain to all handicapped children
- 2) to assure a written record of reasonable expectations, . . . to clarify that such individualized planning conferences are a way to provide parent involvement and protection to assure that appropriate services are provided to a handicapped child (2 United States Congressional and Administrative News: 1435- 1436)

Each state also appropriates monies to fund special education programs. Like any other health and human services program, a disparity exists in the amount of funding each individual

²In 1990, the law was renamed Individuals with Disabilities Education Act (IDEA) to keep this legislation in line with the Americans with Disabilities Act (ADA).

state provides for special education programs. States have challenged the requirement to fund such programs in cases such as *Mills v. Board of Education of the District of Columbia* [348 F.Supp. 866 (D.D.C. 1972)] and *Rainey v. Tennessee* [No. A-3100 (Chancery Court, Davidson County, Tennessee)]; in these cases, the defendants advocated a lack of funds to allow for such programs.

State educational authorities, such as education agencies and commissions, have to assume the responsibility for "effecting a policy that assures a free appropriate public education is being provided by local agencies to all children with disabilities" (Guernsey and Klare, 1993: 6). States have the discretion to interpret the laws within the boundaries set by federal legislation. However, when the provisions of this statute are not met, school districts and other service providers can be challenged in the courts, even the highest court in the United States. The law imposes significant responsibilities on local and state educational authorities to ensure that disabled children are receiving a free, appropriate public education. In addition to ensuring such substantive rights, procedural protections are provided (Guernsey and Klare, 1993: 1).

Zettel and Ballard warn that Public Law 94-142 should not be seen as a "cure all" for all of the handicapped child's educational problems. However, this law should be used as a starting place to help parents, educators, and other professionals solve the problems (Zettel and Ballard, 1982: 20).

Section 504 of the Rehabilitation Act of 1973

Section 504 of the Rehabilitation Act of 1973 was enacted just after *Mills v. Board of Education of the District of Columbia*. The intent of this legislation is to prohibit discrimination based on a person's handicap (Guernsey and Klare, 1993: 2).

One of the problems with implementation of this statute was defining who was covered by Section 504. For handicapped individuals, this means:

. . . any individual who a) has a physical or mental disability which for such individual constitutes or results in a substantial *handicap* to employment and b) can reasonably be expected to benefit in terms of employability from vocational rehabilitation services provided (Gerry and Benton, 1982: 45-46).

Section 504 expanded the basic assumption of civil rights law (Gerry and Benton, 1982: 41). The wording of this law is very similar to the wording of Title VI of the 1964 Civil Rights Act and to the wording of Title IX of the Education Amendments of 1972:

No otherwise qualified handicapped individual in the United States . . . shall, solely by reason of his handicap, be excluded from the *participation* in, be denied the benefits of; or be subjected to discrimination under any program or activity receiving *[f]ederal* financial assistance [29 USC sec. 794 (1983)].

The Act requires entities that receive federal financial assistance to provide proof of compliance. If violations are noted, the entity is required to provide a corrective action plan. The entity is also supposed to designate an employee to coordinate compliance, to adopt grievance procedures, and to give notice to participants that their program "does not discriminate against handicapped persons" (Thomas, 1985 (A): 10).

Section 504 defines a person as handicapped if

he has a physical or mental impairment which substantially limits one or more major life activities, *has* a record of such impairment or is regarded as having such an impairment. . . . Prior to a person being classified as handicapped, it must also be

shown *that a* major life activity (caring for one's self, performing manual tasks, walking, seeing, hearing speaking, breathing, learning, and working) is limited due to the nature of the handicap (Thomas, 1985(A): 11).

"Qualified" (as the term applies to preschool, elementary, and secondary students) means that a handicapped person must be 1) of an age during which nonhandicapped persons are served, 2) of an age during which handicapped persons must be served under state law, or 3) eligible for a "free, appropriate public education" under laws for the handicapped. Aid, benefits, or services provided to handicapped students must be equal to those provided to non-handicapped students. In situations where separate services are permissible, the facilities available to both groups must be equivalent (Thomas, 1985(A): 11).

Responsibility for carrying out the various provisions of Section 504 was given to the United States Office of Civil Rights (Gerry and Benton, 1985: 45). Later, after passage of Public Law 94-142, and because the two statutes address overlapping concerns, the Office of Civil Rights and the Bureau of Special Education Programs were given the responsibility for coordinating their efforts. This coordination has resulted in a consistent definition in both regulations of the basic elements of a "free, appropriate public education" (Gerry and Benton, 1985: 47; Thomas, 1985(A): 12), which is discussed further in the following section.

What are "Free, Appropriate Public Education" and "Least Restrictive Environment"?

On November 29, 1975, President Ford signed Public Law 94-142 into law. This law prescribed many things, but most importantly it prescribed the right to a "free, appropriate public education" and an education in the "least restrictive environment" (Weintraub and Ballard, 1982: 4). These two provisions are, perhaps, simultaneously the most critical and the

most vague of any of the provisions in this particular law. The following discussion will attempt to clarify these phrases.

Free, Appropriate Public Education

What constitutes a "free, appropriate public education" (FAPE)? While no conclusive definition exists, combining the individual definitions of each of these words yields the following:

A free appropriate public education is knowledge or training, gained through study or experience, *that* belongs to the people *as a* whole. This knowledge or training should be suitable *and* proper for the occasion and without unnecessary costs (The World Book Dictionary, World Book - Childcraft International, Inc., Doubleday & Company (1978): 102,670,849, and 1683).

Although this definition is somewhat simplistic, the courts have had difficulty determining exactly what the concept means.

Free, appropriate public education has been called the "cornerstone provision" of Public Law 94-142 (Hyatt, 1981: 6; Woody, 1994: 77). The use of the term "appropriate" in the legislation is purposely vague because of the diversity of handicapping conditions (Hyatt, 1981: 7). However, in Jeffrey Zettel's opinion, the opposite is true. He states that "implementation of a statute as detailed and prescriptive as this law could be problematic" (Zettel, 1982: 23). However, because of the discretion that states have regarding implementation, the law must be purposefully broad in order to address individual needs.

Entities responsible for providing a "free, appropriate public education" have encountered several controversies. These controversies arise in identifying the potential recipients of special services, evaluating the child, preparing the Individual Education Plan once a decision to place the child in special education has been made, deciding on the best possible

placement, and making sure that the specified procedural safeguards are provided to the child and his or her parents (Thomas, 1985(B): 16-17). This controversy has fueled such cases as Board of Education of Hendrick Hudson Central School District v. *Rowley* [458 U.S. 176, 102 S.Ct. 3034, 73 L.Ed. 690 (1982)] and Florence County School District Four v. Carter (102 SCt 3034), which tested the limits of a "free, appropriate public education."³ (Each controversy is discussed below.)

- ▶ **Identification**-- Identification of handicapped children is the responsibility of the entity providing the service and not of the parent. For a parent identification method to work, every parent would have to be educated both on what special education can provide and how their child could benefit from such programs. Once these children are identified, the evaluation process begins (Thomas, 1985(B): 16-17).

To aid in this identification process, parents are encouraged to be active participants and integral members of a "multi-disciplinary team." This team includes school professionals, such as the principal, special education personnel, and the child's regular classroom teacher (if applicable), as well as the parent or guardian. "[Public Law 94-142] envisions parents working cooperatively with teachers and other professionals in

³As stated above, the purposeful vagueness of the Public Law 94-142 is necessary to enable the individual states and school districts to deal with individuals; however, this vagueness can also work against those who must implement the law.

In *Rowley*, the child's right to an appropriate education and placement were not upheld by the school district. However, in *Carter*, the school district's failure to provide a "free, appropriate public education" caused them to pay for that child's placement in a private school. The Supreme Court ordered reimbursement for this private school placement to Shannon Carter's parents because the school district had not made a good faith effort to comply with the requirements of a "free, appropriate public education."

a joint effort to provide appropriate educational programming" (Myers and Jenson, 1984: 402).

Parents can protest this process and request an independent evaluation (Thomas, 1985(B): 16- 17). If the parent feels the evaluation is inappropriate, an independent evaluation can be requested at public expense. However, if it can be proved that the evaluation methods are appropriate, the parents can still request an independent evaluation but at their expense. The committee preparing the child's Individual Education Plan (IEP) must consider the findings of this independent evaluation (Thomas, 1985(B): 19).

If parental consent is not given for evaluation, a decision has to be made whether to place the child in a regular classroom or to pursue the matter further. If regular classroom placement is chosen, the school or placement authority must consider that if the child is actually handicapped, such placement is most likely inappropriate and thus violates the "free, appropriate public education" provision. Also, if the child requires a more restrictive placement because of other unique needs or behaviors, such placement could be a "disadvantageous" choice for both the disabled child and the other children in the regular classroom (Thomas, 1985(B): 18).

Further, if parental consent is not given, then state law has to be consulted to determine what course must be taken, and IDEA appeals procedures can be followed. If it is determined that the child should be evaluated, the parent has several options: to go along with the placement, to appeal the decision to evaluate to the state's education

agency, to withdraw the child from public school and enroll him or her in a private school, or to acquire approval for home instruction (Thomas, 1985(B): 18).

- Evaluation -- Prior to the evaluation, the parents or guardians must be "notified of their procedural rights and must be provided with an explanation of what has and will take place, including a description of each proposed evaluation activity" (Thomas, 1985(B): 18).

If parental consent is obtained, the child must be evaluated to 1) determine if a handicapping condition does exist and if special education is needed, and 2) obtain information for designing the child's Individual Education Plan (Thomas, 1985 (B): 18).

- Individual Education Plan (IEP) -- The Supreme Court has held that an "appropriate placement" means that the child should be provided with "personalized instruction with sufficient services to permit the child to benefit educationally from that placement" (Osborne, 1992: 489). The IEP is part of the attempt to see that the child is appropriately placed and that appropriate services are provided.

The IEP is developed with input from the multi-disciplinary committee (noted earlier) and the child's parents. This meeting is called an ARD -- admission, review, and dismissal. The IEP contains goals and objectives for the individual child and schedules for meeting those goals and objectives. This IEP is reviewed annually, and the child's progress is evaluated (Thomas, 1985(B): 19; Guernsey and Klare, 1993: 7).

- Placement -- Appropriate placement is required in a timely manner. Placement can be either public or private and must represent the least restrictive environment for the

individual child. The placement should also be as close to the child's home as possible (Thomas, 1985(B): 24).

- ▶ **Procedural Safeguards** -- Parents have due process rights when they feel that their child's rights have been violated (Thomas, 1985(B): 26).

Hyatt suggests that the mandate prescribed by this federal legislation has been "reduced to a deceptively simple proposition that every handicapped child is entitled to an appropriate education at public expense in the least restrictive environment" (Hyatt, 1981: 2).

Least Restrictive Environment

Championship prowess will sooner be attained if she concentrates on intensive training and learning to swim before she plunges unprepared into the turbulent mainstream. When her strokes are stronger she will be able to make better headway in the water.

Grkman v. Scanlon
528 F.Supp. 1032, 1037
(W.D. Pa. 1981)

Public Law 94-142 mandates that school districts establish procedures for allowing handicapped students into the regular classroom, as allowed by their handicapping condition. This process is called "mainstreaming"; it is also referred to as "least restrictive environment," or LRE (Jaffe, 1994: 391). Relative to the "free, appropriate public education" requirement, this provision has "provoked more controversy and confusion than any other issue in special education" (Dubow, 1989: 215). Practitioners continuously ask questions about interpretation and implementation of "least restrictive environment" (Hasazi, et al., 1994: 491).

The following are reasons for integrating children with handicaps into a regular classroom setting:

- 1) Handicapped children will be able to achieve more both academically and socially.*
- 2) The exposure to the regular classroom will enable handicapped children to better cope with the "real world" when they are adults.*
- 3) Exposure to handicapped children will help [nonhandicapped] children to better understand individual differences in people (Zettel, 1982: 33).*

The "least restrictive environment" provision has "acknowledged the existence of a wide continuum of educational placements," from the least restrictive (regular classroom) to the most restrictive (institutions or special schools) (Zettel and Ballard, 1982: 17-18). A former Secretary of Education stated that "inherent in a free appropriate public education is a continuum of services, including separate facilities, both public and private" (Dubow, 1989: 216).

The Department of Education has asserted that "least restrictive environment" is a "core value" in special education. According to the author, Congressional intent has been turned into a requirement based on this assertion. "Least restrictive environment" continues to be a primary concern in placement decisions; the author suggests that this concern contradicts "both [c]ongressional intent and judicial interpretations of the Act" (Dubow, 1989: 216). An appeals court stated that ". . . laudable policy objectives must be weighed in tandem with the Act's principal goal of ensuring that the public schools provide handicapped children with a free appropriate public education" [852 F.2d 290 (7th Cir. 1988)].

The Supreme Court has not defined boundaries for determining whether "least restrictive environment" has been met (Jaffe, 1994: 391). In *Oberti v. Board of Education*, the 3rd Court of Appeals found that a child should not be placed in a special classroom if placement

in a "regular classroom" could be successfully accomplished "with supplementary aids and services" (Jaffe, 1994: 392). Federal Courts of Appeals developed tests to determine whether or not a district is in compliance with the "mainstreaming" requirement.

Two tests are used by the federal courts for determining whether or not districts meet the "least restrictive environment" provision of Public Law 94-142: the Roncker test and the Daniel R.R. test.

- ▶ The Roncker test is essentially a cost/benefit analysis. Even if a "superior education" could be provided in a special education classroom, if a "regular classroom" education proved feasible with similar services provided, the regular classroom would be the more appropriate placement. This test came from *Roncker v. Walter* [700 F.2d 1058 (6th Cir.)]. Courts will rule for special classroom placement if the severity of the child's handicap would be detrimental and disruptive to placement in the regular classroom. The 5th Circuit Court of Appeals criticized the Roncker case because it made the court decide on proper placement for the child since that decision is technically a duty of the school district (Jaffe, 1994: 395-396).
- ▶ The Daniel R.R. test came from the case *Daniel R.R. v. State Board of Education* [874 F.2d 1036, 1046 (5th Cir. 1989)]. A two-part test was used to determine compliance with "least restrictive environment": Would placement in a regular classroom with the use of supplemental aids and services be satisfactorily achieved for X child? If a decision was made that it could not, or if the child was to be removed from special education, was the child mainstreamed to the "maximum extent appropriate"? (McColl, 1992: 16).

According to Elizabeth Jaffe, the Daniel R.R. test more accurately and fairly determines if a full or even partial regular classroom placement would work. She states that the Roncker test shows the "impracticability of full integration" (Jaffe, 1994: 400).

When making decisions about "free, appropriate public education" or "least restrictive environment" placements, perhaps educators should take Sy Dubow's advice that a balance must exist between the requirement to educate handicapped children with nonhandicapped children and the need to educate such children in specialized settings and programs (Dubow,

1989: 218). There are no "black and white rules" for making placement decisions (Dubow, 1992: 222). This is important to remember because of the diversity and uniqueness of handicapping conditions and the impact that those conditions have on the children they affect (Hyatt, 1981: 2-3, 7). Each decision must be made on a case-by-case basis (Osborne, 1992: 490; Dubow, 1989: 217).

A Questionable Future

What does the future hold for litigation in the areas covered by Public Law 94-142 and Section 504 of the Rehabilitation Act of 1973? The school districts need to "have their ducks in a row" and make sure that they have truly met the individual needs of the handicapped child in question. Unfortunately, one of the purported "pluses" of these particular pieces of legislation -- particularly the wide administrative discretion for the states within the guidelines set by the law -- is also one of its biggest drawbacks. Questions will exist about what constitutes "free, appropriate public education" or "least restrictive environment" as long as there are handicapped children with varying degrees of need. Unless drastic changes occur, this will always be the case.

Conceptual Framework (Basis for Evaluation)

The following framework will be used to evaluate each of the state policies or recommendations for addressing the needs of medically fragile children:

Table 2.1
Comparative Framework

ELEMENT	TEXAS	MICHIGAN	IOWA
Free Appropriate Public Education			
▶ The handicapped child is evaluated on at least a yearly basis in order to determine the most appropriate setting for his or her educational needs.			
▶ The handicapped child has equal access to facilities such as the school library, gymnasium, cafeteria, and lockers.			
▶ The handicapped child is provided with educational services that will prepare him or her for a job in some segment of his or her community.			
Least Restrictive Environment			
▶ The child is educated along side students in the regular classroom to the greatest extent practical.			
▶ The child is provided access to adequate guidance and direction by a qualified staff member (can be teacher or classroom aide).			
▶ The handicapped child has ample opportunity to interact with nonhandicapped children.			
▶ The ratio of handicapped children to nonhandicapped children is reasonable based on the types of handicapping conditions (i.e. less restrictive handicapping conditions warrant placement in a more "normal" environment, whereas more severe handicaps warrant a more restrictive setting).			
▶ The handicapped child is able to interact with his or her peer group.			

ELEMENT	TEXAS	MICHIGAN	IOWA
Other			
<ul style="list-style-type: none"> ▶ The child is placed in a permanent home situation (i.e. his birth family or with a family that plans to adopt him or her) instead of an institution. 			

Any policy for addressing the needs of children with disabilities must include various elements as mandated by federal law. (These have been discussed in earlier sections of this chapter.) Policies addressing the needs of medically fragile children should include these elements, with particular attention being paid to any component parts. The following discussion provides a justification for inclusion of the selected elements.

- ▶ **The handicapped child is evaluated on at least a yearly basis in order to determine the most appropriate setting for his or her educational needs.** This element is necessary in any policy that addresses the needs of children with handicaps. For children with severe disabilities, and particularly those who are medically fragile, this element is especially crucial because of fragile nature of their disability. Children in this group should be evaluated every six to nine months depending, on their changing health care needs. Placement that might be appropriate during one particular period might not be as appropriate six to nine months later.
- ▶ **The handicapped child is provided with educational services that will prepare him or her for a job in some segment of his or her community.** If it is determined that an individual medically fragile child will benefit from such training, then the training

should be provided. Such training could include computers or any other task appropriate to the developmental level of the child in question.

- The handicapped child has equal access to facilities such as the school library, gymnasium, cafeteria, and lockers. In compliance with the Americans with Disabilities Act, persons with handicaps should have access to anything that nonhandicapped persons do.
- The child is educated along side students in the regular classroom to the greatest extent practical; the handicapped child has ample opportunity to interact with nonhandicapped children; and the handicapped child is able to interact with his or her peer group. According to Stainback, et al., "[h]azards exist when people in authority . . . focus on any one of an individual's characteristics and organize the individual's life around that characteristic." If this focus is perpetuated, it only reinforces the segregation of years past (Stainback, et al., 1994: 488). When children with handicaps are given the opportunity to interact with children who don't have any physical or mental handicaps, each of these children are given the chance to learn about differences in others and, perhaps, to respect those differences.

Likewise, children with handicaps need to be given the chance to interact with children with similar circumstances. It is important for any policy to include planned avenues for the development of support groups in either the school or community setting (Stainback, et al., 1994: 487).

- The child is provided access to adequate guidance and direction by a qualified staff member. Children with special needs, including children who are medically fragile,

need guidance from a team of qualified staff members who are familiar with a particular child's needs and who can lead the child to his or her greatest fulfillment and potential.

- ▶ The ratio of handicapped children to nonhandicapped children is reasonable based on the types of handicapping conditions (**i.e.** less restrictive handicapping conditions warrant placement in a more "normal" environment, whereas more severe handicaps warrant a more restrictive setting). Too many severely disabled children in one classroom can cause undue hardship for the teacher and nonhandicapped student as well as the medically fragile child himself. If a medically fragile child is placed within a "regular" classroom for an art or music class, an aide that can attend to and assist the child with a handicap should be provided. This aide could, perhaps, even serve two students in the same situation.
- ▶ The child is placed in a permanent home situation (**i.e.** his or her biological family or with a family that plans to adopt him or her) instead of an institution. For any child, a permanent, home-type placement is preferable over placement in foster care or in an institution. The same can be said for children with severe disabilities. Children need continuity in order to feel safe and secure (The Center on Human Policy, September 1987: 10).

The following coding system will be used to indicate whether the elements described above exist in an actual policy or as a recommendation, or if the element is not addressed at all:

Code	Definition
Policy	Element exists in policy
Recommendation	Element exists in a recommendation or issue relevant to possible policy.
Not Specifically Addressed	Element does not exist either in a policy or in a recommendation.

Concluding Remarks

Chapter 3 provides both an historical perspective of the development of legislation for the handicapped and particular cases and issues leading up to the passage of Public Law 94-142 and Section 504 of the Rehabilitation Act of 1973. Appendix A includes a table which chronicles federal legislation for the handicapped.

Chapter 3

A Brief History of Legislation for the Handicapped

The purpose of this chapter is to provide a brief history of federal legislation for the handicapped. This chapter provides the legal setting for the case studies and analysis included in Chapter 5.

Introduction and a History

As a wave of disabled soldiers returned from European battlegrounds after World War I, Congress *first* enacted legislation aimed at rehabilitating the handicapped.

James S. Alexander
Minnesota Law Review
1984

For many centuries, disabled persons were thought to be "useless, nonproductive members of society. . . . they were abused, ignored, and ridiculed" (Cremins, 1983(A): 5). Many societies have deemed it easier to ignore them than it was to have to deal with them. An 1834 Kentucky law stated that

[a] person of unsound mind . . . is, as to all intellectual purposes, dead; and such a thing, destitute of intellectual light and life, is as incapable as a dead body of being a husband or wife in a legal, rational, or moral sense [Jenkins v. Jenkins' Heirs 2 Dana 102, 32 Kentucky 102, 104 (1834)].

Although the Declaration of Independence guaranteed Americans the right to pursue life, liberty, and happiness, the opportunities to realize these rights have not been equally and uniformly available to all of America's citizens (Thomas, 1985(A): 1).

In several states, laws were enacted that prohibited a handicapped person from immigrating to the United States, from having a hunting license, or holding office; some states even restricted a newborn's right to life. In *Brown v. Brown* (1821), a person who was deaf, blind, and mentally retarded was considered, by law, to be incapable of understanding anything.

But the early part of the nineteenth century produced evidence that these people could learn things. Numerous schools or "asylums" were established. New Jersey was one of the first states to officially authorize and offer classes for mildly mentally retarded students. However, unless the child was labeled "educable," he or she was still denied access to an education because a child with a "trainable" label demanded too much of a teacher's time (Thomas, 1985 (A): 3). The actual labeling of the "handicapped" legitimized the special treatment and the "provision of differential legal, medical, residential, economic, and socialization care." The labeling was also a "more efficient use of resources and care for the handicapped" (Cremins, 1983(A): 5). In 1823, Kentucky established the first school for the deaf; in 1825, Pennsylvania appropriated funds for a school for the mentally retarded (Weintraub and Ballard, 1982: 1).

Of more significance was a particular school for the deaf; President Abraham Lincoln signed the bill that created this institution (Weintraub and Ballard, 1982: 1). Rev. Gallaudet was the leader of this school, the first "residential school" in the United States. The institution was first known as the "Asylum for the Deaf" and located in Hartford, Connecticut. Just a few years later, a school for the blind was opened, and by the 1850s, "Samuel Gridley Howe had established the Institution for Idiotic Children in Massachusetts" (Cremins, 1983(A): 5).

The declaration of prominent Americans of the period also did much to develop the first service infrastructure for the handicapped. Horace Mann, a prominent educator, stated that

"Every person has a natural law right to an education" (Thomas, 1985(A): 2). Alexander Graham Bell, in a 1898 speech before the National Education Association, reiterated such comments when he said that "handicapped children had a right to an education through the public schools." This was the first mention of such a right; the mandates for this "right" would not be developed for over 80 years (Cremins, 1983(A): 5-6).

The Industrial Revolution and the great migration of people from rural to urban areas contributed to the development of more standard schools for the handicapped (Cremins 1983(A): 5). Vast immigration to the United States added to the demand for special educational services. Immigrants, with cultural and language differences, heightened the need for such institutions. Like the early handicapped, these people were "rejected, ignored, and isolated" (Cremins, 1983(A): 6).

However, the end of the nineteenth century brought a slowing of the progress that had been made in educating the handicapped. The anticipated integration of the handicapped and others with need for special services into society just did not occur. Someone once said that "[t]he goal of society was to train the handicapped to function in the institution rather than educating them to function in society." James Cremins listed four reasons for this shift in thinking:

- 1) The handicapped were ignored while America was caught up in its Industrial Revolution.*
- 2) Few people had the training, interest, or motivation to work with the handicapped,*
- 3) The handicapped were hidden away in secluded institutions and were forgotten about.*
- 4) Society preferred to hide its mistakes (Cremins, 1983(A): 5).*

The first special education teachers were trained at the Lapeer State Home and Training School in Michigan around 1914. The first college program in special education was at Michigan State Normal College. This school was established by Charles M. Elliott; his efforts "resulted in [the] establishment of the Rackman School of Special Education at Eastern Michigan University." This school was the United States' main source of special education teachers for many years.

Despite these efforts, the number of teachers remained low, perhaps due to the initial resistance to deal with this particular population; in 1949, 77 colleges had programs for special children, and by 1953, this number had increased to 122 (Cremins, 1983(A): 7).

Modern legal history of education for disabled children began with *Brown v. Board of Education* [347 U.S. 483 (1954)] (Guernsey and Klare, 1993: 2; Thomas, 1985(A): 4). Children of color, as well as disabled children, often faced either no education or education that was not equal to that received by white children. In *Brown*, it was determined that educating children in separate facilities did not guarantee equality; this case "formed the initial wedge needed by children with disabilities to pry open the schoolhouse door" (Lantzy, 1992: 1; Cremins, 1983(A): 14-15). This corollary between children of color and disabled children was noted in the June 1955 issue of *Children Limited*, the newsletter of the National Association for Retarded Citizens. The editor remarked, 'You will recognize . . . that this statement of equal opportunity applies to the handicapped as it does the minorities' (National Association for Retarded Citizens, *Children Limited*, June 1955: 9).

The handicapped were thought not to be able to receive any benefit from education because they couldn't take proper care of themselves and because they made disruptive noises. Since they actually or apparently willfully violated school rules and policies and disturbed other

students, it appeared that the handicapped did not belong in school. Such cases sometimes went to court, though a school's decision to deny access to education was often upheld if because it had taken a "good faith act" to take remove disruptive behaviors from the school (Thomas, 1985(A): 2-3).

The 1950s brought the development of the National Association for Retarded Children (NARC) and the growth of various other state and local organizations. Public education programs pushed the subject of retardation "out in the open" (Cremins, 1983(A): 7).

Also, in the 1950s, sterilization was the rule in 28 states if a person was feeble-minded, insane, an idiot, an imbecile, or a victim of epilepsy. In several states, marriages could not occur if one of the persons had a mental illness, or was mentally retarded or epileptic (Thomas, 1985(A): 1).

Twenty years elapsed after Brown before the Federal Government passed legislation providing equal educational opportunities for disabled children. One case in particular, Pennsylvania Association of Retarded Citizens (PARC) v. Commonwealth of Pennsylvania [343 F.Supp. 279 (E.D. Pa., 1972)], "signalled the beginning of the end for educational discrimination against [disabled] children" (Cremins, 1983(A): 14-15; Thomas, 1985(A): 4-5). One of the main questions posed in this case resembled a question posed in Brown: "Is a separate education also an equal education?" In PARC, provisions relieving the state of the responsibility to educate children designated "uneducable" or "untrainable" by a school psychologist were struck down. The Court found that mentally retarded children were capable of benefitting from an education that was appropriate to their training and capacity to learn. Furthermore, the state was to provide this education free of charge. This decision further mandated that a mainstream

classroom placement was much preferable to the more segregated options (Thomas, 1985(A): 5).

Another case that questioned equality for the handicapped was *Mills v. Board of Education of the District of Columbia* [348 F.Supp. 866 (D.C.C. 1972)]. In this case, any funds that a state or local district appropriated for education had to be equally distributed between both nonhandicapped and handicapped students so that no child would be denied the opportunity to benefit from an education suited to his or her needs and abilities (Zettel and Ballard, 1982: 13). In *Mills*, the right to an appropriate public education was expanded to include children with behavioral problems, emotional disturbance, and hyperactivity (Thomas, 1985(A): 5).

A prohandicapped sentiment prevailed in the mid- 1960s; Congress began to take steps to guarantee equal rights and due process for handicapped students. These steps included Section 504 of the Rehabilitation Act of 1973 and Public Law 94- 142, The Education of the Handicapped Act of 1975 (Thomas, 1985(A): 6), both of which were discussed in the previous chapter.

The 1960s also brought national leadership in the White House. President John F. Kennedy appointed a panel on mental retardation which suggested that states had a responsibility to "provide and stimulate services for the mentally retarded." State-level programs also began to flourish. Two Congressmen, Lister Hill and John Fogarty, were among the first to introduce legislation specifically addressing the handicapped (Cremins, 1983(A): 8). Even with this action at the national level, policies still excluded children because of "bodily or mental conditions" that made school attendance inadvisable.

Just six years prior to the Mills and PARC cases (1966), Congress added Title VI to the federal Elementary and Secondary Education Act (Public Law 89-750). This title created the Bureau of Education for the Handicapped to provide leadership for identifying desirable trends in the education for the handicapped.

In 1970, Public Law 91-230 was signed into law, as amendments to the Elementary and Secondary Education Act. This passage repealed Title VI of that act and created the Education for All Handicapped Children Act which generated some of the most far-reaching and positive changes that the field of special education had experienced in several years (Myers and Jenson, 1984: 401). Part B of this legislation authorized grants to assist the states and school districts in "initiating, expanding, and improving" educational programs for disabled children. With this and future amendments to Public Law 91-230, such as Senate Bill 896, the Federal Government acted as more of a catalyst than a true regulator in that it provided support for the growth of state and local programs (2 United States Congressional and Administrative News 75-49).

In 1975, Congress passed Public Law 94-142, further amending Public Law 91-230. This legislation "streamlined" the original funding provisions of Public Law 91-230

1) to focus the distribution of funds to the states based on an incentive *formula* relative to the actual delivery of services by a time certain to all handicapped children

2) to assure a written record of reasonable expectations. . . . to clarify that such individualized planning conferences are a way to provide parent involvement and protection to assure that appropriate services are provided to a handicapped child (2 United States Congressional and Administrative News: 1435-1436)

Further, this amendment makes a formal statement for the provision of a "free, appropriate public education." In 1990, the law was renamed Individuals with Disabilities Education Act (IDEA) to keep the title of this legislation in line with the recently passed Americans with

Disabilities Act (ADA). "As of late 1991, Congress had passed six substantive amendments to the original Act, reflecting Congressional efforts to institutionalize a national policy based on the philosophy of a 'right to education for all children'" (Lantzy, 1992: 3).

Summary and Concluding Remarks

From the inception of public education until the early 1950s, children who were "different," including children of color and disabled children, were discouraged, or even barred from receiving the benefits of "free, public school education." Moreover, even after the *Brown v. Board of Education* [347 US 483, 495 (1954)] decision, both children with handicapping conditions and children of color were still left outside the mainstream of public education. Nonetheless, the *Brown* decision provided the needed impetus for such children, their parents, and guardians to "nudge their way in" and demand the same rights as children of color (Lantzy, 1992: 1). In *Brown*, the Supreme Court stated that a child could not be expected to succeed in life if certain educational opportunities were denied to him or her. Further, that opportunity must be provided to all children and on "equal terms" [347 US 483, 493 (1954)]. In other words, children had a fundamental right to an education.

The 1970s are probably the most significant period in the development of legislation for the disabled. Several states and ultimately federal law adopted legislation, and courts sanctioned such legislation, that stated that the handicapped had basically the same rights as any other person in this country (Cremens 1983(A): 8). Two of the most important pieces of legislation, Section 504 of the Rehabilitation Act of 1973 and Public Law 94- 142, were discussed in detail in Chapter 2.

Chapter 4 reviews and discusses the research methodologies chosen for this project, case study and document analysis. Justification for the choice of these methods will be presented.

Chapter 4

Research Methodology

This applied research project is an exploratory study which uses analysis of existing documents and the case study approach to gather and analyze the data. In this chapter, the methodologies of document analysis and case study approach are discussed, along with the strengths and weaknesses of both methods. A discussion of the documents obtained for analysis, as well as the manner in which the documents were obtained, is also provided.

Both document analysis and the case study approach are forms of unobtrusive research. Such research methods provide the researcher with several benefits, including saving time, money, and manpower. However, weaknesses of such an approach include questions of data accuracy and validity and the limitations of recorded communications.

Document Analysis

According to Guba and Lincoln, researchers looking at documents for purposes of analysis are interested for several things:

[They are interested in] making inferences about the values, sentiments, intentions, beliefs, or ideologies of the sources or authors of the documents; they sometimes want to make inferences about group or societal (or personal) values: and they sometimes want to evaluate the effects of communications on the audiences that they reach (Guba and Lincoln, 1981: 237).

In this study, the main documents for analysis were obtained through various methods. The initial information for this study was obtained through a colleague, Bryan Jones, an employee of the Texas Rehabilitation Commission. This information was part of a report that the Texas

Rehabilitation Commission had obtained for their review of programs for medically fragile children across the United States. Through a review of this information, the states for analysis were chosen. Specific information on programs or recommended policies for such programs was provided for the State of Michigan, with its Permanency Program, and the State of Iowa, through a report from the Alliance for Parent Partnership.

Safeguarding Our Future: Children and Families First, produced by the Commission on Children and Youth, was obtained by calling the Commission. Another report, Children in Texas Who Are Medically Fragile in Texas was obtained from the Texas Council on Developmental Disabilities. A report produced by the Institute for Quality in Long Term Care at Southwest Texas State University, Medically Fragile Children: A Comparison of State Programs, was obtained from the researcher's coworker at the Texas State Auditor's Office.

A series of unstructured interviews were conducted by phone with various employees of the Iowa Department of Human Services. The purpose of this series of interviews was to obtain information regarding follow-up information about Consider the Children, a report prepared by the Alliance for Parent Partnership, an advocacy group within Iowa. The first question asked was "Do you have any knowledge of programs for severely disabled or medically fragile children?" A follow-up question asked whether the employee had heard of Consider the Children. The researcher talked to several persons within this Department, but no assistance was available.

However, after a conversation with Gerd Claybaugh, Office of Public Health, the researcher was directed to the Office of Public Policy within the Iowa Department of Human Services. After a brief conversation with Becky Cook, Office of Public Policy, information from

Consider the Children was faxed to Ms. Cook. Several weeks later, a response in the form of legislation for a family assistance program was received.

The information for the State of Michigan was the information that was obtained initially from a colleague. An attempt was made to obtain the detailed report on the state's Permanency Program by mail; a follow-up letter was sent three weeks after the first. However, to date, the report has not been received. (Some of the difficulty in obtaining this information stems from the instructions listed within the article to only request information through the mail.) This lack of a detailed description of the Permanency Program limits the conclusions that can be drawn for the State of Michigan.

Case Study Approach

Schramm stated that "the essence of a case study. . . is that it tries to illuminate a decision or set of decisions: why they were taken, how they were implemented, and with what result" (Schramm, 1971, as stated in Yin. 1994: 14). In Chapter 5, a case study approach will be used to compare and evaluate three individual state policies (or recommendations for such policies) against the elements of "free, appropriate public education" and "least restrictive environment." (See Chapters 2 and 3 for detailed information on these elements.)

This segment explores why particular elements are included in an individual state's program, how those elements are being or will be implemented, and, if available, the results of that implementation. [Note: There is no policy in place in Texas at this time; however, recommendations for such a policy have been developed by the Texas Commission on Children

and Youth in a report titled *Safeguarding Our Future: Children and Families First* (December 1994).]

A disadvantage to using the case study approach is the subjective nature of such interpretations. According to Guba and Lincoln, "writer biases or errors in judgment cannot easily be detected" (Guba and Lincoln, 1981: 377). Also, this technique is heavily researcher dependent. These factors can contribute to a lack of strength in the validity of the research. As stated earlier, replication of the study may not be possible because of this subjectivity in interpretation.

The elements of the individual policies or recommendations for policies will be evaluated through answering a series of questions about "free, appropriate public education" and "least restrictive environment." These questions include the following:

- **free, appropriate public education**

Is the child provided with an individualized education? Are there provisions that mandate evaluation of the child's plan on at least a yearly basis? Is the program that is to be provided to the child centered on the child, or is the program centered on the system or on results? Is the education provided at public expense? Does it include all levels of the child's education?

- **least restrictive environment**

Are educational services rendered to children with handicaps equal to services rendered to nonhandicapped children? Are adequate educational environments available for the child? Is the child given opportunities to interact with children who are not handicapped?

The results will be coded using the criteria in the following table:

Code	Definition
Policy	Element exists in policy
Recommendation	Element exists in a recommendation or issue relevant to possible policy.
Not Specifically Addressed	Element does not exist either in a policy or in a recommendation.

Concluding Remarks

Chapter 5 presents the situation for the medically fragile in Texas and an overview of the situation in Michigan and Iowa. Following the case study and overview will be a comparison, analysis, and evaluation of the policies currently in place or the recommendations for such policies, as the case may be.

Chapter 5

Case Study and Analysis

Chapter 5 serves several purposes:

- 1) to present the situation for the medically fragile in Texas
- 2) to present an overview of the situation in Michigan and Iowa
- 3) to compare, analyze, and evaluate the above data

The Situation for the Medically Fragile in Texas

Children who are medically fragile are a rapidly growing population. These . . . [are] children who 10 or 20 years ago would surely have died. [They] are first and foremost children. And their families are first and foremost families -- families with regular needs, wants, and ambitions.

from Children In Texas Who Are Medically Fragile:
Their Families' Voices
page I

In December **1993**, the Austin American-Statesman published a series of articles by reporter Denise Gamino, titled "The Lost Children." that described the difficult situation that medically fragile children face. Many of these children live in nursing homes or other institutions, while others live at home with parents, foster parents, or guardians. Several articles in this series detailed the deplorable living conditions and the lack of educational or other learning opportunities that these children live with.

Because of this series of articles. Lt. Governor Bob Bullock called for immediate action to address this issue. Several committees were convened, including the Commission on Children and Youth, which was led by Senators Jim Turner and Allen Hightower. The Commission

produced the report, *Safeguarding Our Future: Children and Families First*. Two reports were also produced for the Senate Health and Human Services Committee: *Children in Nursing Homes: A Comprehensive Report*, which was produced by the Texas Health and Human Services Commission, and *Medically Fragile Children: A Comparison of State Programs*, which was prepared by the Institute for Quality Improvement in Long Term Health Care, School of Health Professions, Southwest Texas State University.

Overall, the reports described the various services and service delivery systems that are in place in Texas and other states. **As** evidenced by the Quality Improvement in Long Term Health Care's report, these programs are numerous and provided by a number of agencies.

[A] parent or guardian that attempts to access these services or a professional attempting to guide a family in obtaining the needed services is faced with a system that appears confusing, *fragmented*, and overlapping (Institute for Quality Improvement in Long Term Health Care, August 1994: 17).

Table 5.1 illustrates the vast diversity of services and the many agencies where parents, guardians, and children must go to obtain such services.

Table 5.1
Texas Health and Human Services
Programs for Children with Severe Disabilities

AGENCY	PROGRAM	MEDICAL ELIGIBILITY	SERVICES
Interagency Council on Early Childhood Intervention	Early Childhood Intervention	Children under three years of age, developmental disabilities, medical conditions that could result in delay	Screening and assessment; training in skills; case management; array of direct services

**Texas Health and Human Services
Programs for Children with Severe Disabilities**

AGENCY	PROGRAM	MEDICAL ELIGIBILITY	SERVICES
Texas Department of Mental Health and Mental Retardation (TXMHMR)	Targeted case management for mental retardation or related conditions	Mental health or mental retardation condition	Targeted case management
	Home-Based Community Services-OBRA	Mental retardation or related condition with inappropriate placement in nursing home	Case management, adaptive aids, dietary, respite, homemaker, nursing, habilitation, occupational therapy, physical therapy, speech, audiology, social, psychology services
	Intermediate Care Facility -mental retardation or related conditions	Based on income, functional limitations	Residential and adjunctive services
	In-home family support services **	Mental illness, mental retardation, autism, or developmental disabilities (ages 0-4)	Special equipment, architectural modifications, counseling, respite, transportation, health services
	Home-Based Community Services	Receives/received Supplemental Security Income; Intermediate Care Facilities; mental retardation levels I, V, or VI	Case management, adaptive aids, dietary, respite, homemaker, nursing, habilitation, occupational therapy, physical therapy, speech, audiology, social, psychology services
Texas Department of Protective and Regulatory Services (TDPRS)	Children with Disabilities Project	Children in TDPRS conservatorship or at risk of abuse/ neglect	Education care givers, respite, recruitment, foster homes, linkage to resources/services
Texas Rehabilitation Commission	Deaf-Blind; Multi- handicapped Program	Deafness and Blindness	Residential Care; supports; summer camps

**Texas Health and Human Services
Programs for Children with Severe Disabilities**

AGENCY	PROGRAM	MEDICAL ELIGIBILITY	SERVICES
Texas Department of Human Services	Day activity and health services	Functional disability related to medical diagnosis	Nursing, personal care, transportation, social/educational/recreational services
	In-Home and Family Support Services ***	Four years of age and older; physical disability	Special equipment, architectural modifications, counseling, respite. transportation, health services
	Primary Home Care	Limitation in personal care; based on medical condition	Personal care; home management; escort
	Medically Dependent Children Program	21 years of age or younger; requires services of a licensed nurse	In-homelout of home licensed nursing service and facility based respite care
	Community Living Assistance and Support Services	Intermediate Care Facility for mental retardation or related condition level of care	Case management, special equipment, architectural modifications, nursing, respite. psychological, physical and occupational therapy. speech, adaptive aids/supplies
	Nursing Facility Care	Medically Needy; Pre- admission Screening and Annual Resident Review	Total medical, nursing, and psychological needs - residential
	Intermediate Care Facility - Mental Retardation Program	Level of Care	Institutional care for mentally retarded or related conditions

**Texas Health and Human Services
Programs for Children with Severe Disabilities**

AGENCY	PROGRAM	MEDICAL ELIGIBILITY	SERVICES
Texas Department of Health	Child Health Services		Health Evaluation and Education
	Children with Special Health Care Needs	"Certain medical conditions are covered"; ages 0-20	Evaluation, direct medical care, case management
	Immunization Program		Immunization distribution and tracking, consultation, epidemic investigation
	Texas Medical Assistance Program (Medicaid)		Comprehensive health care services; early periodic screening, diagnosis, and treatment program
	Program for Amplification for Children in Texas	Hearing difficulty that interferes with educational advancement	Diagnosis, hearing aids and service, counseling
	Childhood Lead Prevention Program	6 months - 6 years of age with abnormal blood levels of lead	Surveillance and prevention - for professionals
	Newborn screening program	All newborns	Testing for PKU, galactosemia, congenital hypothyroidism, sickle cell disease, adrenal hyperplasia
	School Health Program		Start-up funding for model school health centers
	Speech Language Screening Program		Training of screeners
	Spinal Screening Program	10-14 years of age	Screening, training, data collection, education
	Vision and Hearing Screening		Training of screeners

Source: Institute for Quality in Long Term Health Care. School of Health Professions, Medically Fragile Children: A Comparison of State Programs, August 1994, pages 17- 18.

Given the diversity and complexity of these programs, parents and medically fragile children need a more efficient service delivery system. For parents and their children to access the variety of services portrayed in the above table, they would have to be extremely well informed about the processes of state government. Children of this population many times cannot wait for services, especially if these services would prolong their lives or otherwise be of benefit to them. For example, a child with cerebral palsy needs a wheelchair to get around. This child also has mental retardation. In order for this child to receive educational services, the parent would have to go to the Department of Mental Health and Mental Retardation to receive services that address the needs created by mental retardation and to the Department of Human Services or the Rehabilitation Commission to receive services that address the needs created by cerebral palsy.

In *Safeguarding Our Future: Children and Families First*, the Commission on Children and Youth presented two recommendations that address the educational needs/development of special children:

- 1) Require developmentally appropriate curriculum and instructional practices for early childhood education programs (page 151).
- 2) Include students with disabilities in regular classrooms (page 155).

Although the first recommendation does not specifically refer to severely handicapped or medically fragile children, with the discretion for development of details that this option gives to the local school district, the policy-making body within that school district can tailor the programs to meet the needs of individual children (*Safeguarding Our Future: Children and Families First*, December 1994: 155).

To address the recommendation for including students with disabilities in the regular classroom, the report mentioned a policy statement that had been adopted by the State Board of Education in July 1994. The policy statement, titled *Policy Statement on the Education of Students With Disabilities*, says that the "ultimate goal of service delivery for students with disabilities is their integration and participation in the general education program when it meets the identified of each student" (*Safeguarding Our Future: Children and Families First*, December 1994: 155). This policy reinforces the guidelines for "least restrictive environment" outlined in Public Law 94-142.

The State of Texas is also in the process of developing 190 "inclusion pilot projects" across the State. However, according to the report, "This is only a small step in beginning to meet the needs of all disabled children across the state [sic]" (*Safeguarding Our Future: Children and Families First*, December 1994: 155).

An Overview of Two Other States: Michigan and Iowa

"There's no place like home. There's no place like home."

"Dorothy" in *The Wizard of Oz*

The State of Michigan has "paved the way" for other states in the area of permanency planning for medically complex and medically fragile children. Permanency planning represents a change in priorities, from a concentration on the disability or disabilities that the child has to a more "holistic" or "big picture" approach that focuses on the child first (Center on Human

Policy, September 1987: 9). (This change in approach mirrors the "shift in thinking" that was led by passage of the Americans with Disabilities Act in 1990.)

Permanency planning redirects thinking regarding placement decisions from the institution -- hospital or nursing home -- to a family or home placement. This placement decision is the first priority of permanency planning. Even foster care is thought of as a "placement of last resort" because of the preference for continuity and stability for children, especially those with disabilities. When placement with the birth family is not a viable option and family reunification efforts fail, administrators of this plan in Michigan aggressively pursue adoption for the child. Again, this is due to the theory that "home is best." If adoption is the only alternative, and if it is in the best interest of the child, the program makes every effort possible to keep the child and the birth family involved (Center on Human Policy, September 1987: 9).

The Permanency Planning Program, in existence since 1983, is the oversight entity in the State of Michigan. The program began under a grant from the federal Administration on Children, Youth, and Families. One of the major goals is to redirect funds away from out-of-home placement and into support of families. This support includes respite care, case management, assistance with physical modifications to the home, etc. For families with children with disabilities, this type of support is especially crucial (Center on Human Policy, September 1987: 10).

Iowa

The State of Iowa has a policy with goals similar to those of Michigan. In an act titled *Creating a Personal Assistance Services Program for Persons with Disabilities and a Comprehensive*

Family Support Program for Families of Persons with Disabilities, Iowa provides a more definitive outline for their state with regard to coordination with the Americans with Disabilities Act. The act contains several key provisions that are similar to those contained in Michigan's Permanency Plan.

This act called for the creation of an eleven-member Council that is made up solely of parents of children with a disability or an adult who has a disability. The charge of the Council is to develop a program plan, budget, and funding for two programs: 1) Personal Assistance Services for Adults⁴ and 2) Comprehensive Family Support for Families with Children Who Have Disabilities.

The mission of Personal Assistance and Family Support Council is to develop a program that will keep individuals of all abilities in the home, promoting the ideals of family unity and consumer empowerment. For the child, the family is the most knowledgeable about what supports are needed and appropriate. For an adult, each person is the most knowledgeable about his or her own needs and supports. This program will be user friendly and flexible and will facilitate the person's independence and full participation as a productive member of the community of his or her own choice (Personal Assistance Services: Program Design, Budget, and Funding Plan, November 1994).

⁴Comprehensive Family Support refers to services or other assistance intended to enable an individual with a disability to control their environment, to remain living with their family, to function more independently, and to increase their integration into their community.

Comparison, Analysis, and Evaluation

Based on the documents reviewed. Texas is the only state of the three examined that addresses any type of educational issue. In *Safeguarding Our Future: Children and Families First*, the Commission on Children and Youth makes two specific recommendations that address "free, appropriate public education" and "least restrictive environment": "Require developmentally appropriate curriculum and instructional practices for early childhood education programs" and "Include students with disabilities in regular classrooms" (*Safeguarding Our Future: Children and Families First*, 1994: 151, 155)

The working hypotheses, as originally set out in the research prospectus dated December 29, 1994, are as follows:

- 1) If the elements of a "free, appropriate public education" are found within an individual state policy, it is expected that an individual segment of the policy can be considered to be effective.
- 2) If the elements of a "least restrictive environment" are found within an individual state policy, that segment of the policy can be considered to be effective.
- 3) Overall, if 75 percent of the elements for each of the provisions are evaluated as meeting the "requirements" of a "free, appropriate public education" and "least restrictive environment," it is expected that the individual state policy, or recommendation for such a policy, can be considered to be effective.

Based on the results of the study, these working hypotheses are not supported. This outcome could be contributed to the limited scope of the project, which was to review policies and recommendations for addressing the educational needs of medically fragile children.

The following framework contains elements of an "ideal" policy for addressing the educational needs of a medically fragile child, as expressed by the review of Public Law 94-142

and Section 504 of the Rehabilitation Act of 1973 (contained in Chapter 2), and a summary of the results of the review of the various reports examined. (Notes for clarification purposes are provided if deemed necessary.) The following table provides a review of the coding system that is used:

Code	Definition
Policy	Element exists in policy
Recommendation	Element exists in a recommendation or issue relevant to possible policy.
Not Specifically Addressed or Does Not Exist	Element does not exist either in a policy or in a recommendation.

Table 5.2
A Comparison of Texas, Michigan, and Iowa

ELEMENT	TEXAS	MICHIGAN	IOWA
Free Appropriate Public Education			
<ul style="list-style-type: none"> ▪ The handicapped child is evaluated on at least a yearly basis in order to determine the most appropriate setting for his or her educational needs. 	Not specifically addressed	Not specifically addressed	Not specifically addressed
<ul style="list-style-type: none"> ▪ The handicapped child has equal access to facilities such as the school library, gymnasium, cafeteria, and lockers. 	Not specifically addressed	Not specifically addressed	Not specifically addressed
<ul style="list-style-type: none"> ▪ The handicapped child is provided with educational services that will prepare him or her for a job in some segment of his or her community. 	Not specifically addressed	Not specifically addressed	Not specifically addressed

ELEMENT	TEXAS	MICHIGAN	IOWA
Least Restrictive Environment			
<ul style="list-style-type: none"> The child is educated along side students in the regular classroom to the greatest extent practical. 	Recommendation	Not specifically addressed	Not specifically addressed
<ul style="list-style-type: none"> The child is provided access to adequate guidance and direction by a qualified staff member (can be teacher or classroom aide). 	Recommendation	Not specifically addressed	Not specifically addressed
<ul style="list-style-type: none"> The handicapped child has ample opportunity to interact with nonhandicapped children. 	Recommendation	Not specifically addressed	Not specifically addressed
<ul style="list-style-type: none"> The ratio of handicapped children to nonhandicapped children is reasonable based on the types of handicapping conditions (i.e. less restrictive handicapping conditions warrant placement in a more "normal" environment, whereas more severe handicaps warrant a more restrictive setting). 	Recommendation	Not specifically addressed	Not specifically addressed
<ul style="list-style-type: none"> The handicapped child is able to interact with his or her peer group. 	Recommendation	Not specifically addressed	Not specifically addressed
Other			
<ul style="list-style-type: none"> The child is placed in a permanent home situation (i.e. his birth family or with a family that plans to adopt him or her) instead of an institution. 	Recommendation	Policy	Policy

Summary and Concluding Remarks

This chapter discussed the issues regarding medically fragile children in Texas, with a comparison to situations in Michigan and Iowa. Chapter 6 presents a summary of the applied research project and provides recommendations for change.

Chapter 6

Summary and Concluding Remarks

Chapter 6 serves several purposes:

- to summarize the results of the analysis presented in Chapter 5
- ▶ to make recommendations for about the current systems
- ▶ to make projections about the future of funding for such programs and possible future amendments to Public Law 94-142

Summary of Results

In the policies and recommendations examined, it was found that issues and policies related to medically fragile children focused mainly on the health-related concerns and permanency placement issues. This is evidenced by Michigan's Permanency Program and the mission of Iowa's Personal Assistance and Family Support Council. These policies and recommendations are concerned with a more basic right than education: the right to a home and family. Most of the policies and recommendations reviewed addressed health care delivery issues and placement issues overall rather than to address education specifically.

The report, *Safeguarding Our Future: Children and Families First*, included issues and several recommendations related to the education of "at-risk" children in the State of Texas. Two issues in particular, "Require developmentally appropriate curriculum and instructional practices for early childhood education programs" and "Include students with disabilities in regular classrooms." address the "free, appropriate public education" and "least restrictive environment" provisions of Public Law 94-142 that were discussed in Chapter 2. However,

these elements only address the elements of "least restrictive environment" that were included as the "ideal educational policy for medically fragile children."

Recommendations and Projections

Each state should adopt a policy that mandates a certain level of care and education for medically fragile children. The service delivery system should be streamlined, and services provided under an "umbrella entity," not like the multitude of entities that currently provide services in Texas. (See Table 5.1 for an example of the current service delivery system in Texas.) The services currently being provided by the multiple entities should be examined to make certain that no duplication or overlap exists.

What if states had more definitive and stringent guidelines for implementation of the Individuals with Disabilities Education Act? Would the litigation stop? Would more exact guidelines for specifying a "free, appropriate public education" help reduce or even stop litigation? Would those who support less Federal Government involvement in state and local affairs be willing to sacrifice the opportunities they now have to determine their own policies and procedures in certain areas, or would they welcome the extraguidance?

It is the opinion of this researcher that, although the courts might have an easier time saying "yes, this is appropriate" or "no, this isn't appropriate," the citizens affected would find the extragovernmental control over their lives chafing. Over the past 20 years or so, a movement has occurred which proposes placing more control at the state and local level and less at the Federal Government level. This process began during the Nixon administration and continued through the Reagan years. Even though a more definitive "right way/wrong way" interpretation

would make it easier to decide what exactly constitutes "free, appropriate public education," this researcher believes that the majority of the citizenry would balk at that extra measure of control. Moreover, given the issues discussed earlier, such as the inherent vagueness and subjectivity of the term "appropriate," Congress would have a very difficult time coming to closure on this issue.

One of the current reform movements in Congress is to give states block grants instead of money that the states would have to match. The states would have the discretion to use the money as they wished, within certain guidelines. Perhaps this would be an option for funding services for the medically fragile child.

Concluding Remarks

The initial scope of this project was very limited; it only addressed the educational needs of medically fragile children. Perhaps this was a bit shortsighted on the part of the researcher. Is education all that matters, or should the scope have been broadened to include the provision of other services for these children? Is education of medically fragile children viable, or should the money that would be spent on such adventure be better spent on programs for the less severely handicapped or even nonhandicapped child? These are questions that should be answered, especially in today's world of rising costs and program cuts. However, if medical technology has advanced to the point where even the most severely ill children can be kept alive, shouldn't society be able to find some way to provide the best possible life for severely disabled and medically complex children?

Appendix A:
Federal Laws for the Handicapped (through 1981)

TITLE OF FEDERAL LEGISLATION	DATE OF ENACTMENT	PUBLIC LAW NUMBER
An Act to provide for the location of the two townships of land reserved for a seminary of learning in the territory of Florida, and to complete the location of the grant to the Deaf and Dumb Asylum of Kentucky	January 29, 1827	19-8
An Act to extend the time for selling the lands granted to the Kentucky Asylum for teaching the deaf and dumb	February 18, 1847	29-11
An Act to establish in the District of Columbia a Government Hospital for the Insane	March 3, 1855	33-4
An Act to establish the Columbia Institute for the Deaf and Dumb	February 16, 1857	34-56
An Act to incorporate the Columbia Institution of the Deaf and Dumb and the Blind	February 16, 1857	34-46
An Act to amend the "Act to incorporate the Columbia Institution of the Deaf and Dumb and the Blind"	May 29, 1858	35-59
An Act making appropriations for sundry civil expenses of the government (first appropriations bill)	June 12, 1858	35-154
An Act to authorize the Columbia Institution for the Deaf and Dumb and Blind to confer degrees	April 8, 1864	38-52
An Act making appropriations for sundry civil expenses of the government for the year ending June 30, 1865, and for other purposes	July 2, 1864	38-210
An Act to amend an Act entitled, "An Act to incorporate the Columbia Institution for the Instruction of the Deaf and the Dumb and Blind	February 23, 1865	38-50

TITLE OF FEDERAL LEGISLATION	DATE OF ENACTMENT	PUBLIC LAW NUMBER
An Act making appropriations for sundry civil expenses of the government for the year ending June 30, 1868, and for other purposes	March 2, 1867	39-167
An Act to amend existing laws relating to Internal Revenue and for other purposes	March 2, 1867	39-169
An Act to promote the education of the blind	March 3, 1879	45-186
An Act regulating postage on letters written by the blind	July 7, 1898	55-HR4304
An Act to promote the circulation of reading matter among the blind	May 27, 1904	58-171
An Act to modify the requirements of the Act entitled "An Act to promote the education of the blind," approved March 3, 1879	June 25, 1906	59-288
An Act making appropriations for the services of the Post Office Department for the fiscal year ending June 3, 1913, and for other purposes	August 24, 1912	62-336
Vocational Rehabilitation Act (for discharged military personnel)	June 27, 1918	65-178
An Act providing additional aid for the American Printing House for the Blind	August 4, 1919	66-24
An Act to provide for promotion of vocational rehabilitation of persons disabled in industry or otherwise and their return to civil employment	June 2, 1920	66-236
An Act providing additional hospital facilities for patients of the Bureau of War Risk Insurance and of the Federal Board for Vocational Education, Division of Rehabilitation, and for other purposes	March 4, 1921	66-384
An Act to establish a Veterans' Bureau and to improve the facilities and services of such bureau and further to amend and modify the War Risk Insurance Act	August 9, 1921	67-47

TITLE OF FEDERAL LEGISLATION	DATE OF ENACTMENT	PUBLIC LAW NUMBER
An Act amending Subdivision 5 of Section 302 of the War Risk Insurance Act	December 18, 1922	67-370
An Act to authorize an appropriation to enable the Director of the United States Veterans Bureau to provide additional hospital facilities	June 5, 1924	68-197
An Act to amend sections 1, 3, and 6 of an Act entitled, "An Act to provide for the promotion of vocational rehabilitation of persons disabled in industry or otherwise and their return to civil employment"	June 5, 1924	68-200
An Act to incorporate the United States Blind Veterans of the World War	June 7, 1924	68-218
World War Veterans' Act of 1924	June 7, 1924	68-242
An Act to amend paragraph (1) of section 22 of the Interstate Commerce Act by providing for the carrying of a blind person, with a guide, for one fare	February 26, 1927	69-655
An Act to amend the Act providing additional aid for the American Printing House for the Blind	February 8, 1927	69-584
An Act to amend an Act entitled, "An Act to provide for the promotion of vocational rehabilitation of persons disabled in industry or otherwise and their return to civil employment"	June 9, 1930	71-317
An Act to provide books for the adult blind	March 3, 1931	71-787
To amend an Act entitled, "An Act to provide for the promotion of vocational rehabilitation of persons disabled in industry or otherwise and their return to civil employment," approved June 2, 1920, as amended	June 30, 1932	72-222
To amend section 1 of the Act entitled "An Act to provide books for the adult blind," approved March 3, 1931	March 4, 1933	72-439

TITLE OF FEDERAL LEGISLATION	DATE OF ENACTMENT	PUBLIC LAW NUMBER
To amend the Act entitled, "An Act to promote the circulation of reading matter among the blind," approved April 27, 1904, and Act supplemental thereto	May 9, 1934	73-214
To authorize an increase in the annual appropriation for books for the adult blind	June 14, 1935	74-139
Social Security Act	August 14, 1935	74-271
To authorize the operation of stands in federal buildings by blind persons, to enlarge the economic opportunities of the blind, and for other purposes	June 20, 1936	74-732
To provide special rates of postage on matter for the blind	April 15, 1937	75-37
To authorize an increase in the annual appropriation for books for the adult blind	April 23, 1937	75-47
To amend the Interstate Commerce Act (seeing eye dogs)	July 5, 1937	75-184
To amend the Act approved August 4, 1919, as amended, providing additional aid for the American Printing House for the Blind	August 23, 1937	74-339
United States Housing Act of 1937	September 1, 1937	75-412
To amend the Acts for promoting the circulation of reading matter among the blind	May 16, 1938	75-523
To create a Committee on Purchases of Blind-made products and for other purposes--Wagner-O'Day Act of 1938	June 25, 1938	75-739
To amend the Act entitled "An Act to provide books for the adult blind," approved March 3, 1931	June 7, 1939	76-118
Social Security Amendments of 1939	August 10, 1939	76-379

TITLE OF FEDERAL LEGISLATION	DATE OF ENACTMENT	PUBLIC LAW NUMBER
To amend the Act entitled, "An Act to provide books for the adult blind," approved March 3, 1931	June 6, 1940	76-562
To further amend the Acts for promoting the circulation of reading matter among the blind	October 14, 1941	77-270
To permit seeing eye dogs to enter government buildings when accompanied by their blind masters, and for other purposes	December 10, 1941	77-330
To amend section 1 of the Act entitled, "An Act to provide books for the adult blind," approved March 3, 1931, as amended	October 1, 1942	77-726
To amend Title I of Public Law Number 2, 73rd Congress, March 30, 1933, and the Veterans Regulation to provide for rehabilitation of disabled veterans, and for other purposes	March 24, 1943	78-16
Vocational Rehabilitation Act Amendments of 1943	July 6, 1943	78-113
To provide revenue, and for other purposes or "The Revenue Act of 1943"	February 25, 1944	78-235
To amend the Act entitled "An Act to provide books for the adult blind"	June 13, 1944	78-338
Servicemen's Readjustment Act	June 22, 1944	78-346
To amend the Act entitled "An Act to provide books for the adult blind"	August 8, 1946	79-661
Social Security Act Amendments of 1946	August 10, 1946	79-719
Revenue Act of 1948	April 2, 1948	80-471
To amend the Civil Service Act to remove certain discrimination with respect to the appointment of persons having any physical handicaps to positions in the classified civil service	June 10, 1948	80-617

TITLE OF FEDERAL LEGISLATION	DATE OF ENACTMENT	PUBLIC LAW NUMBER
To maintain status quo in respect of certain employment taxes and social security benefits pending action by Congress on extended social security coverage	June 14, 1948	80-642
Authorizing an appropriation for the work of the President's Committee on National Employ the Physically Handicapped Week	july 11, 1949	81-162
To permit the sending of braille writers to or from the blind at the same rates as provided for their transportation for repair purposes	September 7, 1949	81-290
Social Security Act Amendments of 1950	August 28, 1950	81-734
To restore to seventy pounds and one hundred inches in girth and length combined the maximum weight and size limitations for appliances or parts thereof for the blind sent through the mails	April 9, 1952	82-308
To amend the Act approved August 4, 1919, as amended, providing additional aid for the American Printing House for the Blind	May 22, 1952	82-354
To amend the Act entitled "An Act to provide books for the adult blind"	July 3, 1952	82-446
Social Security Act Amendments of 1952	July 18, 1952	82-590
To change the Columbia Institution to Gallaudet College, define its corporate powers, and provide for its organization and administration and other purposes	June 18, 1954	83-420
To authorize cooperative research in education	July 26, 1954	83-531
Vocational Rehabilitation Amendments of 1954	August 3, 1954	83-565
Social Security Amendments of 1954	September 1, 1954	83-761

TITLE OF FEDERAL LEGISLATION	DATE OF ENACTMENT	PUBLIC LAW NUMBER
To amend the Interstate Commerce Act in order to authorize common carriers and such attendants at the usual fare charged for one person	July 27, 1956	84-825
Social Security Amendments of 1956	August 1, 1956	84-880
To amend the Act to promote the education of the blind, approved March 3, 1879, as amended, so as to authorize wider distribution of books and other special instructional material for the blind, to increase the appropriations authorized for this purpose, and for other purposes	August 2, 1956	84-922
To amend an Act entitled "An Act to provide books for the adult blind"	September 7, 1957	85-308
Social Security Amendments of 1958	August 28, 1958	85-840
National Defense Education Act of 1958	September 2, 1958	85-864
To provide in the department of Health, Education, and Welfare a loan service of captioned films for the deaf	September 2, 1958	85-905
To encourage expansion of teaching in the education of mentally retarded students through grants to institutions of higher learning and to state educational agencies	September 6, 1958	85-926
Housing Act of 1959	September 23, 1959	86-372
Social Security Amendments of 1960	September 13, 1960	86-778
To make available to children who are handicapped by deafness the specially trained teachers of the deaf needed to develop their abilities and to make available to individuals suffering speech and hearing impairments the specially trained speech pathologists and audiologists needed to help them overcome their handicaps	September 22, 1961	87-276

TITLE OF FEDERAL LEGISLATION	DATE OF ENACTMENT	PUBLIC LAW NUMBER
To amend the Act to promote the education of the blind, approved March 3, 1879, as amended, so as to authorize wider distribution of books and other special instruction materials for the blind, and to increase the appropriations authorized for this purpose, and to otherwise improve such Act	September 22, 1961	87-294
Public Welfare Amendments of 1962	July 25, 1962	87-543
To authorize the employment without compensation from the Government of readers for blind Government employees, and for other purposes	August 29, 1962	87-614
To provide for the production and distribution of educational training films for use by deaf persons, and for other purposes	September 28, 1962	87-715
To establish in the Library of Congress a library of musical scores and other instructional materials to further educational, vocational, and cultural opportunities in the field of music for blind persons	October 9, 1962	87-765
To amend the Public Health Service Act to provide for the establishment of an Institute of Child Health and Human Development	October 17, 1962	87-838
Social Security Act Amendments of 1963	October 24, 1963	88-156
Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963	October 31, 1963	88-164
To authorize the President to issue annually a proclamation designating the first week in March of each year as "Save Your Vision Week"	December 30, 1963	88-242
Hospital and Medical Facilities Amendments of 1964	August 18, 1964	88-443
To authorize the President to proclaim October 15 of each year as "White Cane Safety Day"	October 6, 1964	88-628

TITLE OF FEDERAL LEGISLATION	DATE OF ENACTMENT	PUBLIC LAW NUMBER
Social Security Amendments of 1964	October 13, 1964	88-641
Social Security Amendments of 1964	October 13, 1964	88-650
Elementary and Secondary Education Act of 1965, as amended	April 11, 1965	89-10
National Technical Institute for the Deaf Act	June 8, 1965	89-36
Social Security Amendments of 1965	July 30, 1965	89-97
Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1965	August 4, 1965	89-105
Community Health Service Extension Amendments of 1965	August 5, 1965	89-109
Heart Disease, Cancer, and Stroke Amendments of 1965	October 6, 1965	89-239
Captioned Films for the Deaf Act	October 19, 1965	89-258
Federal Assistance to State Operated and Supported Schools for the Handicapped	November 1, 1965	89-313
Vocational Rehabilitation Act Amendments of 1965	November 8, 1965	89-333
Library Services and Construction Act Amendments of 1966	July 19, 1966	89-511
An Act to provide books for the adult blind	June 30, 1966	89-522
Fair Labor Standards Amendments of 1966	September 23, 1966	89-601
Military Benefits Amendments of 1966	September 30, 1966	89-614
Model Secondary School for the Deaf Act	October 15, 1966	89-694
Comprehensive Health Planning and Public Health Services Amendments of 1966, "Partnership for Health"	November 3, 1966	89-749
Elementary and Secondary Education Act Amendments Act of 1966	November 3, 1966	89-750

TITLE OF FEDERAL LEGISLATION	DATE OF ENACTMENT	PUBLIC LAW NUMBER
Higher Education Act Amendments of 1966	November 3, 1966	89-752
Mental Health Amendments of 1967	June 24, 1967	90-31
To amend Title V of the Higher Education Act of and redesignate it as the Educational Professions Development Act	June 29, 1967	90-35
Vocational Rehabilitation Amendments of 1967	October 3, 1967	90-99
To amend the Library Services and Construction Act	November 24, 1967	90-154
Mental Retardation Amendments of 1967	December 4, 1967	90-170
Partnership for Health Amendments of 1967	December 5, 1967	90-174
Postal Revenue and Federal Act of 1967	December 16, 1967	90-206
Elementary and Secondary Education Act Amendments of 1967	January 2, 1968	90-247
Social Security Amendments of 1967	January 2, 1968	90-248
Vocational Rehabilitation Amendments of 1968	July 7, 1968	90-391
To increase size of the Board of Directors of Gallaudet College	July 23, 1968	90-415
To establish a register of blind persons in the District of Columbia, to provide for the mandatory reporting of information concerning such persons and for other purposes	August 3, 1968	90-458
Elimination of Architectural Barriers to Physically Handicapped	August 12, 1968	90-480
Establishment of National Eye Institute	August 16, 1968	90-489
Handicapped Children's Early Education Assistance Act	September 30, 1968	90-538
Health Services and Facilities Amendments of 1968	October 15, 1968	90-574

TITLE OF FEDERAL LEGISLATION	DATE OF ENACTMENT	PUBLIC LAW NUMBER
Higher Education Amendments of 1968	October 16, 1968	90-575
Vocational Rehabilitation Amendments of 1968	October 16, 1968	90-576
To authorize the President to issue a proclamation designating the first week in June of 1969 as "Helen Keller Memorial Week"	May 28, 1969	91-17
To provide for a National Center on Educational Media and Materials for the Handicapped and for other purposes	August 20, 1969	91-61
Older Americans Act Amendments of 1969	September 17, 1969	91-69
Tax Reform Act of 1969	December 30, 1969	91-172
To insure that certain federally constructed facilities be constructed so as to be accessible to the physically handicapped	March 5, 1970	91-205
To extend the Migrant Health Act for three more years, and provide increased authorization therefor	March 12, 1970	91-209
To extend programs of assistance for elementary and secondary education	April 13, 1970	91-230
Postal Reorganization Act	August 12, 1970	91-375
To broaden National Employ the Physically Handicapped Week to apply to all handicapped workers	October 8, 1970	91-442
To provide long-term financing for expanded urban mass transportation programs	October 15, 1970	91-453
To revise certain criteria for handling mentally retarded persons in the Forest Haven Institution in the District of Columbia	October 22, 1970	91-490
Developmental Disabilities Services and Facilities Construction Amendments of 1970	October 30, 1970	91-517

TITLE OF FEDERAL LEGISLATION	DATE OF ENACTMENT	PUBLIC LAW NUMBER
To improve family planning services and population research activities of the Federal Government	December 24, 1970	91-572
To authorize Gallaudet College to maintain and operated the Kendall School as a demonstration elementary school for the deaf	December 24, 1970	91-587
Occupational Safety and Health Act of 1970	December 29, 1970	91-596
Housing and Urban Development Act of 1970	December 31, 1970	91-609
To extend for one year the authorization for various programs under the Vocational Rehabilitation Act	December 31, 1970	91-610
To provide assistance in developing and administering lead-based paint elimination programs	January 13, 1971	91-695
Wagner-O'Day Amendments	June 23, 1971	92-28
Military Medical Benefits Act	July 29, 1971	92-58
Revenue Act of 1971	December 10, 1971	92-178
Intermediate Care Amendments of 1971	December 28, 1971	92-223
Free or reduced- rate transportation for attendants for the blind	June 22, 1972	92-316
Education Amendments of 1972	June 23, 1972	92-318
Social Security Benefit Increase	July 1, 1972	92-336
Maternal and Child Health Amendments	July 10, 1972	92-345
Economic Opportunity Amendments of 1972	September 19, 1972	92-424
Rights of the blind and other physically handicapped in the District of Columbia	October 21, 1972	92-515
National Advisory Commission on Multiple Sclerosis Act	October 25, 1972	92-563

TITLE OF FEDERAL LEGISLATION	DATE OF ENACTMENT	PUBLIC LAW NUMBER
Small Business Investment Act Amendments of 1972	October 27, 1972	92-595
Social Security Amendments of 1972	October 30, 1972	92-603
Older Americans Comprehensive Services Amendments of 1973	May 3, 1973	93-29
National Autistic Children's Week	June 15, 1973	93-42
Health Programs Extension Act of 1973	June 18, 1973	93-45
Maternal and Child Health Amendments	July 1, 1973	93-53
Renegotiation Act Amendments	July 9, 1973	93-66
Committee for Purchase of Products and Services of the Blind and Other Handicapped	July 30, 1973	93-76
Federal Aid Highway Act of 1973	August 13, 1973	93-87
Rehabilitation Amendments of 1973	September 26, 1973	93-112
Domestic Volunteer Services Act of 1973	October 1, 1973	93-113
Amtrak Improvement Act of 1973	November 3, 1973	93-146
Lead-Based Paint Poisoning Prevention Amendments	November 9, 1973	93-151
Social Security Amendments of 1973	December 31, 1973	93-233
Supplemental Security Income Benefits	March 28, 1974	93-256
General Education Amendments	April 18, 1974	93-269
National School Lunch and Child Nutrition Act of 1974	June 30, 1974	93-326
Extend Food Stamp Eligibility to SSI Recipients	July 8, 1974	93-335
National Research Act	July 12, 1974	93-348
Wagner-O'Day Act Amendments	July 25, 1974	93-358

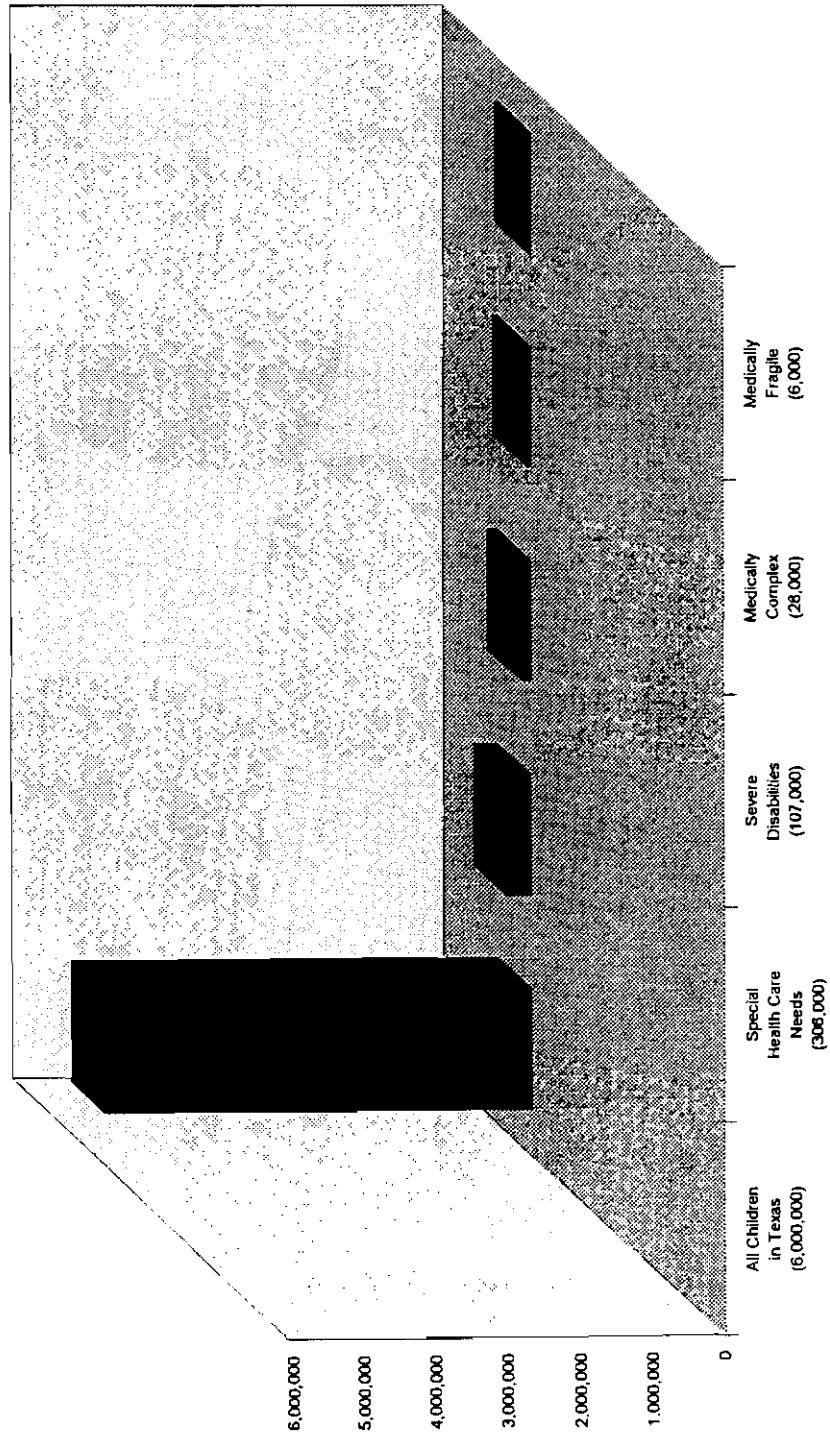
TITLE OF FEDERAL LEGISLATION	DATE OF ENACTMENT	PUBLIC LAW NUMBER
Foreign Equipment Import Duty (Social Security rider)	August 7, 1974	93-368
Education Amendments of 1974	August 21, 1974	93-380
Housing and Community Development Act of 1974	August 22, 1974	93-383
Juvenile Delinquency and Prevention Act of 1974	September 7, 1974	93-415
Import Duty on Horses (Social Security rider)	October 26, 1974	93-484
National Mass Transportation Assistance Act of 1974	November 26, 1974	93-503
Rehabilitation Act Amendments of 1974	December 7, 1974	93-516
March of Dimes Month	December 30, 1974	93-561
National Arthritis Act of 1974	January 4, 1975	93-640
National Health Planning and Resources Development Act of 1974	January 4, 1975	93-641
Federal-Aid Highway Amendments of 1974	January 4, 1975	93-643
Community Services Act of 1974	January 4, 1975	93-644
Social Services Amendments of 1974	January 4, 1975	93-647
To extend SSI to continue food stamp eligibility for recipients	June 28, 1975	94-44
Education for All Handicapped Children Act	November 29, 1975	94-142
The Education Amendments of 1976 (strengthens provisions for handicapped youth in vocational education)	October 12, 1976	94-482
The Education Amendments of 1978 (includes Gifted and Talented Children's Education Act of 1978 and includes extension of provisions of PL 94-142 to Department of Defense Overseas Schools)	November 1, 1978	95-561

TITLE OF FEDERAL LEGISLATION	DATE OF ENACTMENT	PUBLIC LAW NUMBER
The Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978	November 6, 1978	95-602
An Act to Create a Federal Department of Education (established Office of Special Education and Rehabilitative Services)	October 17, 1979	96-88
The Omnibus Budget Reconciliation Act of 1981 (includes Education Consolidation and Improvement Act of 1981)	August 13, 1981	97-35

Source: Ballard, Joseph, Bruce A. Ramirez, and Frederick]. Weintraub, editors. "Federal Laws for the Handicapped." Special Education in America: Its Legal and Governmental Foundations. The Council for Exceptional Children (Reston, Virginia): 1982, 91-99.

Appendix B: Charts and Graphs

UNIVERSE OF CHILDREN IN TEXAS



NUMBER AND PROFILE OF MEDICALLY FRAGILE AND SEVERELY DISABLED CHILDREN (February 1994)

Prepared by the Texas Health and Human Services Commission

DESCRIPTION OF TEXAS CHILDREN, AGE 0-17	NUMBER (1992)	PERCENTAGE OF ALL TEXAS CHILDREN
All Texas children	5,208,809	100.00%
<i>By general severity of disability:*</i>		
Children with diagnosed disabilities (physician identified or diagnosed chronic physical or mental condition)	217,052	4.2%
Children with functional disabilities (same, but condition hinders child's ability to engage in everyday activities without help from other people or from special equipment or devices)	74,584	1.4%
<i>By severity of medical condition:**</i>		
Children with special health care needs (health conditions that last for at least one year, cause a limitation in function, activities, or development and require medical care and related services)	104,176 - 260,440	2 - 5%
Medically complex children (medical problems require 24-hour medical, nursing, or health supervision or intervention)	10,418 - 26,440	.2% - .5%
Medically fragile children (medically complex children who are also technology dependent)	1,042 - 5,209	.02% - .1%
<i>By severity of cognitive or developmental condition:***</i>		
Children with developmental disabilities (mental and/or physical impairments that cause severe deficits in at least 3 major activities of daily living -- such as self-care, language, learning, and mobility -- and will require life-long services)	156,264	3.0%
Children with moderate mental retardation (IQ 35-49)	15,626	.3%
Children with severe or profound mental retardation (IQ below 34)	5,208	.1%

*Source: Department of Human Services Special Texas Census using 1992 population data

**Source: National Maternal and Child Health Statistics reported by the Texas Department of Health and applied to 1992 population data by the Texas Health and Human Services Commission

***Source: Texas Department of Mental Health and Mental Retardation statistics applied to 1992 population data by the Texas Health and Human Services Commission.

Executive Summary

Children In Texas Who Are Medically Fragile

Their Families' Voices



July 1993

The Texas Planning Council for Developmental Disabilities (TPCDD) and the Texas Respite Resource Network (TRRN) contracted with Ilene Gray for this report which is based on a survey of parents with children who are medically fragile -- to ascertain family perceptions, insights, needs and problems, to examine pertinent issues, and to increase public awareness of the wrenching problems these families face. The study was conducted between December 1992 and May 1993, incorporating 223 surveys. Copies of the full report are available from TPCDD, 4900 N. Lamar Blvd., Austin, TX 78751-2399; (512) 483-4080.

Children In Texas Who Are Medically Fragile

Their Families' Voices

Executive Summary

"My husband and I get so tired. We get frightened. Sometimes we think that we can no longer manage. But our children are our joy and are worth it -- always!"

Children who are medically fragile are a rapidly growing population. These children with ongoing, serious medical needs; children with rare conditions or birth anomalies; children who survive illnesses or injuries, but with resultant severe functional limitations; children who 10 or 20 years ago would surely have died; are first and foremost children. And their families are first and foremost families -- families with regular needs, wants, and ambitions.

For these children and their families, the going can be terribly rough, complicated, frustrating, exhausting, and scary. These children have life-threatening health conditions that require constant vigilance, endless patience, and extraordinary care. Their families often need special medical equipment, the help and advice of many health professionals, training, emotional and physical support, and periods of respite so that they can gather the strength needed to continue to care for their children. Most cope somehow, often finding joy, inspiration, and fulfillment as they nurture their children. Others, especially those lacking in community-based services and support, become too exhausted or dispirited to continue to care for their children at home.

The number of families needing in-home services has increased for several reasons, including the "deinstitutionalization" movement. For many families, long-term care facilities such as nursing homes, state schools, and ICF-MR facilities are a last alternative.

Unfortunately, money tends to be more available for institutional or residential services than for services in community settings. A growing body of data has documented the cost-effectiveness of care at home for a majority of children who are medically fragile. National statistics, in general, document a savings of 1/6 to 1/2 of the cost of institutional care when a child is served at home.

More importantly, growing up at home and in a family nurtures children and helps ensure that they have quality lives. There is no substitute for the love and lifelong commitment that family members have for each other.

This report reveals the extraordinary lengths to which so many families go to keep their children at home. They continually overcome overwhelming odds and barriers -- ranging from extensive financial pressures to physical and emotional exhaustion -- to remain together.

Furthermore, families and children want to live in and be part of a community. Community services are critical for families with children who are medically fragile to remain together. These families should not be torn apart and forced to seek institutional care for their children just because services and supports they need to stay together are not available in the community.

Survey Results

- **The Population** -- 223 families from across the state returned the survey.

- ☐ 94% of the families care for their children at home.
- ☐ 160 different diagnoses were reported, with almost all of the children having several disabilities. The most common diagnosis were cerebral palsy, seizure disorders, mental retardation, hydrocephalus and quadriplegia.
- ☐ 70% of the children used some type(s) of equipment or technology. The most common types are: wheelchair (106 times), gastrostomy tube (74 times), suction machine (56), continuous feedings (32), oxygen (29), gavage feedings (21), apnea monitor (19), nebulizer (18), tracheostomy (17), helmet (14), bathing chair (9), IV therapy/c-lines (8), bladder catheter (8), stander (8), walker (7), braces (6), and computer (6).
- ☐ Only 52 of the children (23%) could walk without assistance.

- ❑ 85% of the children used therapeutic service(s) including occupational therapy (147), speech therapy (133), physical therapy (120), and respiratory therapy (46).
 - ❑ 69% of the children had been hospitalized in the past year – some more than a dozen times.
 - ❑ Most parents spend considerable money out-of-pocket for special care. The monthly amount most frequently reported was \$200, and the largest amount reported was \$2,030.
- ❖ **Services: Quality Generally Good; Amount Woefully Insufficient --** Many programs in Texas help families of children with complex medical needs. Respondents enthusiastically lauded the quality of most services, but pointed out the severe shortage of services. Many stressed the sometimes awkward and disquieting position in which they felt vulnerable and unable to manage without help. They pointed out that the very lives of their children often depended on the availability of services. Services needed most were respite, in-home care and SSI.
 - ❖ **Navigating the Maze --** Services for families with children who are medically fragile are provided through a variety of public and private programs using different definitions of 'medically fragile,' different eligibility criteria, and different provider qualifications and pay scales. The inconsistencies in service delivery requirements have produced a fragmented service delivery system which is confusing for both providers and parents. Coping with this compartmentalized and fragmented system can be demoralizing and discouraging.
 - ❖ **The Middle Class Gap --** Middle class parents often sharply feel the injustice of a system that excludes them from eligibility for many of the programs they so desperately need. Most programs have income eligibility criteria which frequently do not take into account the higher costs of caring for their child, and many respondents expressed bitterness and anger about the inequitable system.
 - ❖ **Emotional and Physical Exhaustion --** Parents get tired. They become weary, frustrated, and overwhelmed. They feel guilty and often wonder if they can continue to cope. They love their children deeply. But the constant care tries the endurance of the hardiest souls.

- **The Priority Needs: Respite, Respite, and Respite** -- The most frequently and ardently voiced need was for more, **better**, and more affordable respite -- both in and away from families' homes. Because of the exhaustion that comes with the constancy of demands, families need respite so that they can regroup, get some rest, and fortify relationships with other family members, their churches, their friends, and their communities.
- **"Regular" Kids, "Regular" Families** -- While children who are medically fragile certainly have special needs and problems, they are first and foremost kids -- regular kids -- with regular thoughts, emotions, and concerns. They want friends. They want to 'do their own things.' They want to be accepted by their peers. They want to participate in many activities.
- ❖ **The Siblings** -- The relationships between the child who is medically fragile and **his/her** siblings were most often described as very positive: loving, close, and protective. But some **understandable** frustrations, ambivalence, and jealousy were reported by **approximately one-third** of the respondents. **Older** siblings **worried** about eventually becoming responsible for care of the child.
- ❖ **Approaching Adulthood: What Next?** -- The transition to adulthood is particularly difficult. Parents recognize that their child may not achieve the degree of independence hoped for and they **worry** about who will provide services and supports after they are unable to provide or arrange for them.
- ❖ **An Often Wrenching Decision: Residential Placement** -- 87% of the respondents indicated that they never considered institutional placement. Most were vehemently opposed. Parents who had placed children in other living environments generally did so because they felt that they were absolutely incapable of continuing to care for their child at home. They frequently cited the scarcity of support services as contributing to their decision.
- ❖ **Unsung Heroes and Daily Miracles** -- People who care for children who are medically fragile -- parents, siblings, foster families, grandparents -- cheer each new development, each new skill, each barrier overcome. They display a phenomenal amount of patience, love, endurance, tenacity, and warmth.

Next Steps

Many efforts are underway to improve services for children who have complex medical needs. Additional progress will require the ongoing, active involvement of many key players -- families, advocacy groups, representatives of public and private agencies and organizations, and government officials. It is recommended that they:

- ☐ Continue to work for the expansion of community-based services, in part by redirecting institutional dollars to family support services.
- ☐ Foster statewide development of public/private partnerships to provide more alternatives and resources for families.
- ☐ Work to make more services available to middle class families.
- ☐ Improve information and referral and coordinated case management services for families.
- ☐ Work to include the needs of children who are medically fragile in health care and insurance reform.
- ☐ Amplify the means for assessing and documenting how many children are medically fragile and the cost/benefit ratio of community-based services.

Conclusion

An overwhelming majority of parents prefer to care for their children who are medically fragile at home. When this is not possible, there should be good options from which to choose -- where children can grow up in a home and with a family. Community services should be more available to more families and should be aimed at maintaining the well-being, comfort, safety, and positive interactions of the family with the community and society.

If policies and funding streams continue to move further toward enhancing the abilities of families to be self-respecting, independent, and productive; if they increasingly foster holistic, compassionate investment in individual children's lives; and if they effectively tap and coordinate the tremendous resources in most communities, payoffs will be gratifying at the level that matters most -- the lives of families who care for children who are medically fragile.

Medically Fragile Children: A Comparison of State Programs

A Report Prepared for the Senate Committee on Health and Human Services, Texas State Legislature, through the Institute for Quality Improvement in Long Term Health Care, School of Health Professions. Southwest Texas State University, August 1994.

Executive Summary

The issues involving the care of our medically complex children are enormous in scope. This report attempts to define the issues, examine working programs, and offer suggestions as to plausible solutions.

Persons involved in formation of public policy and provision of vital services must focus primarily on the children with the specific intent of allowing an array of options that can be tailored for individual recipients and care givers. Systems must be accessible and feasible.

As the health care industry evolves, options for medically fragile children must also evolve so that all children in need of services can receive those services through care delivery systems that are efficient, safe, and cost-effective while enabling the highest quality of life possible.

Recommendations

- Develop a methodology at the community level to provide what the consumer requests.

- Restructure services to eliminate duplication and to eliminate access barriers.

- Implement independent case management at the community level.

- Allow all groups (parents, providers, agencies) input in formation of public policy.

- Continue 1-800 number to help families locate resources.

- Continue the interagency workgroup. Include a parent.

- Foster academic linkages.

- Establish an accessible database which tracks medically fragile children from birth onward.

- Implement a cost reimbursement system that covers expenditures for the medically fragile children in nursing homes.

- Develop suitable data collection forms for children in nursing homes. The MDS+⁵ is not appropriate.

⁵Minimum Data Set Plus, a documentation system used by nursing homes to collect data for nursing home patients. MDS+ was originally designed for geriatric patients and does not lend itself well to the needs of pediatric patients.

From Consider the Children, a report from the Alliance for Parent Leadership, Johnston, Iowa, September 1993

INTRODUCTION

Over 100 parents, professionals, policy makers, and consumer advocates attended a conference September 20-21, 1993 in Johnston, Iowa, to seek ways to improve health care for children with disabilities and chronic illnesses. The theme of the Partners in Care Leadership Institute was *Health Care Reform: What it Means for Children with Special Health Care Needs and Their Families*. The Institute was funded in part by a grant from the Maternal and Child Health Bureau (Title V, Social Security Act), U.S. Public Health Service, Department Health and Human Services.

The report provides recommendations developed at the Institute, other participant feedback, the program agenda, and a list of participants.

A main objective of the Institute was to develop recommendations that many groups could benefit from and take action on. (Those recommendations follow.) They are targeted to, among others, the Iowa Legislature and Governor's Office, the Iowa Health Reform Council, health care professionals, and families. Parents and other participants developed the recommendations during focus group sessions on the following topic areas:

- ▶ Basic health care benefits package
- Improving access to care for children with special health care needs
- ▶ Making the health care, human services, and educational systems family-centered
- ▶ Empowering families and providers through information and training

The grouping of recommendations in this report mostly reflects the work of individual focus groups, though now and then it seemed helpful to move a statement to a different heading. Recommendations by more than one group are typically not repeated. For example, all four groups had recommendations for increasing parent participation in policy making and for improving the system of care coordination.

Copies of this report are being disseminated widely in Iowa and nationally. Following the Institute, project staff also presented a preliminary set of the recommendations in testimony to an Iowa Health Reform Council subcommittee, and in a targeted mailing. As additional follow-up to the Institute, several community forums on health reform are being planned for late Spring of 1994.

PERSPECTIVES

Who are children with special health care needs? In federal legislation, the term "children with special health care needs" refers to children and youth with or at risk for disabilities and chronic illnesses who require something beyond routine health care. They include children with or at risk for cerebral palsy, sensory deprivation, mental retardation, developmental disabilities, hemophilia, asthma, spina bifida, other genetic disorders, and health-related educational and behavioral problems. An estimated 10 to 30 percent of American children experience health conditions which continue for an extended period or even a lifetime. Compared to other children, these children have a greater number of health-related needs, require a greater number of medical and other professional services, and require these services over a greater period of time and in a greater number of settings. They also have higher health costs.

What problems do they have accessing health care? A myriad of barriers can make it hard or impossible for children with special health care needs to get necessary care and coverage for services. The Institute participants mentioned these barriers:

- Policies that exclude pre-existing conditions
- Adverse decisions about "medical necessity" and "appropriate provider"
- Policies that pay for long-term care in institutions but not in a child's own home
- Maximum caps set on units of service, number of days, etc.
- The lack of caps on out-of-pocket costs for premiums, deductibles, and co-payments
- Turf issues and lack of coordination across agencies and programs
- Health care providers who pick and choose who they will serve
- No transportation to and from services, or transportation that can't accommodate wheelchairs and medical equipment
- Shortage of specialty care providers, especially in rural areas
- Negative attitudes toward "poor" people
- Confusing, conflicting, and inaccurate information, forms that aren't user friendly, and lack of interpreter services

What do families want from the health care system? Parents who attended the Institute talked about the kind of partnership they want with health professionals. They described a family-centered health care system in the following ways:

- "Families are viewed and treated as equal partners with health professionals."
- "The child and siblings are recognized as having valuable input and are included in discussions."
- "Mutual trust exists between the family and health care providers."
- "Families receive complete information on a child's condition and their options for care."
- "Parents have choices about a child's care manager or advocate."
- "Information is in layman terms and someone is available to explain it."

"Families don't have to sacrifice so many resources for the sake of one child."
"Health professionals are sensitive to the practical difficulties of rural families."
(Scheduling multiple visits, transporting equipment, etc.)
"Health professionals give parents time to digest and adjust to negative news about a child."

WHAT SHOULD IOWA'S STANDARD HEALTH BENEFITS PLAN INCLUDE?

Decision makers must recognize that "what's good enough for most lowans" is not enough for children with special health care needs. Health policy for these children must be anchored in the principle of "whatever it takes" to preserve and promote healthy development and to prevent premature death, secondary disability, and unnecessary institutional placements.

RECOMMENDATIONS

- I. Assure that children with special health care needs have access to a comprehensive set of coordinated, family-centered, community-based health care services. The standard health care benefits plan should include the following for these children:
 - ▶ Comprehensive primary and specialty medical and surgical services
 - ▶ Preventive services (prenatal, immunizations, well-child, and other wellness programs)
 - ▶ Durable and non-durable medical equipment and supplies, adaptive devices, and assistive technology (including customized prosthetics and orthotics, wheelchairs, and communication devices)
 - ▶ Mental health/mental illness/substance abuse services
 - Care coordination and case management
 - Nursing/nursing aide provided in home and community settings, e.g., day care centers and schools
 - ▶ Diagnostic services
 - ▶ Ongoing assessments and consultation (health, nutrition, developmental, behavioral)
 - ▶ Occupational therapy and physical therapy
 - ▶ Prescription medications and some over the counter
 - Respite care
 - ▶ Hospice
 - ▶ Home and vehicle modifications
 - Personal assistant services for activities of daily living e.g., bathing, dressing
 - ▶ Special nutritional products, e.g., special formulas and supplements
 - ▶ Dental services
 - ▶ Vision-related services and devices
 - ▶ Speech, language, and hearing devices
 - ▶ Transportation to and from health services
 - ▶ Family planning services

- Genetic counseling
 - Comprehensive emergency services, e.g., ambulance, life flight
2. Maintain all services now offered under Iowa's Medicaid Home and Community-Based Waiver programs.
 3. Provide families with the option of seeking non-traditional treatments and programs.

WHAT SHOULD BE DONE TO IMPROVE ACCESS TO CARE?

RECOMMENDATIONS

Remove or make flexible any caps on therapies, long-term care, and other services for children with chronic conditions.

Put limits on what a family has to pay out of pocket for premiums, deductibles, and co-payments.

Make mobile specialty clinics more available, and let families decide where they go for services.

Establish and maintain a system of exceptions to policy and waivers to assure flexibility in services for children with disabilities and chronic illnesses.

Strengthen the system of care coordination and case management. Ensure that each child with special needs has a written health care plan. Allow health care providers other than physicians to serve as case managers.

Simplify the release of information process and other paperwork.

Improve coordination of multiple specialty appointments, and make the physician's office more user-friendly (e.g., less waiting time, more time with physician, and evening and Saturday appointments).

Make emergency and travel funds available, especially for families who must travel long distances to obtain care.

Create incentives so that physicians, physician assistants, pediatric nurse practitioners, and therapists will make long-term commitments to serve in specific geographic areas.

Provide financial support for development of regional transportation plans. Develop the plans with customer involvement and include the use of volunteers and existing resources such as elderly transportation services.

Allow children to go across state lines if needed to obtain specialty services.

Assure that basic rights are protected. These include confidentiality, the right to informed consent, the right to access medical records, the right to obtain second opinions and independent evaluations, the right to appeal, the right to substitute decision making for those who can't make decisions for themselves, and the right to refuse treatment.

HOW CAN WE MAKE THE HEALTH CARE SYSTEM MORE FAMILY-CENTERED?

RECOMMENDATIONS

- I. Incorporate in the Iowa Health Reform Council's proposal to the Governor the "principles of family-centered care" proposed by former Surgeon General C. Everett Koop. (These principles follow.) These principles should also be incorporated into other policy documents.

KEY PRINCIPLES OF FAMILY-CENTERED CARE

- ▶ Recognizing that the family is the constant in the child's life while service systems and personnel fluctuate.
- ▶ Facilitating family/professional collaboration at all levels of health care: care of individual child; program development, implementation, and evaluation; and policy formation.
Honoring racial, ethnic, cultural, religious, and socioeconomic diversity of families.
Recognizing family strengths and individuality and respecting different methods of coping.
Sharing complete and unbiased information with families on a continuing basis and in a supportive manner.
- ▶ Encouraging and facilitating family-to-family support and networking.
- ▶ Understanding and incorporating the developmental needs of infants, children, and adolescents and their families into health care systems.
Implementing comprehensive policies and programs that provide emotional and financial support in meeting the needs of families.
Designing accessible health care systems that are flexible, culturally competent, and responsive to family-identified needs.

Source: MCHB Fact Sheet, Maternal and Child Health Bureau. U.S. Department of Health and Human Services.

2. Adopt the Iowa Comprehensive Family Support Bill.
3. Adopt legislation that mandates involvement of parents of children with special needs and adults with disabilities on policy boards of health alliances, quality assurance committees, and state agencies.
4. Establish an 800 number for families to call when they have problems with the health care system. This can also be used to collect data to track and solve problems.

5. Recruit parents of children with special health care needs to serve as paid staff members and as volunteers on governing boards and Parent Advisory Committees of hospitals, home health care agencies, and other health organizations.
6. Create a system to measure and assure quality of services and customer satisfaction.
7. Bring parents of children with special needs and adults with disabilities together to build emotional and financial resources in the community.

HOW CAN WE EMPOWER FAMILIES AND PROVIDERS THROUGH INFORMATION AND TRAINING?

RECOMMENDATIONS

1. Create a central clearinghouse with a 1-800 number for health-related information, health benefits counseling, and training for families, health care providers, and other people. The clearinghouse should be linked to multiple community outlets (hospitals, schools, Area Education Agencies) and could be used for parent matching and disseminations of brochures to physician's offices.
2. Develop a train-the-trainer program using parents of children with special health care needs as paid trainers for other parents and providers.
3. Create a system, possibly using public health nurses, to disseminate region-specific information about available resources.
4. Continue research on the causes of and successful treatments for developmental disabilities and chronic health conditions.

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