

Pediatricians and the Education of Children with Disabilities

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Pediatricians and the Education of Children with Disabilities

“Disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society. Improving educational results for children with disabilities is an essential element of our national policy of ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities.”

P.L. 105-17 Individuals with Disabilities Education Act¹

Pediatricians frequently interact with local school system(s) and have a number of critical roles to play for families in their practice whose children require special education services. The year 2002 will mark the 25th anniversary of the full implementation of P.L. 94-142, The Education for All Handicapped Children’s Act. The 1990 reauthorization of the Education of the Handicapped Act (EHA) renamed it as the Individuals with Disabilities Education Act (IDEA). IDEA has transformed the practice of special education and developmental pediatrics by providing a legal foundation upon which services for children with disabilities can be built. In this article, we will 1) review the history of the special education laws, 2) outline provisions of IDEA most relevant to pediatric practice, 3) detail accomplishments and challenges of the special education legislation, and 4) discuss implications of the special education process for child health providers.

CELEBRATING THE 25TH ANNIVERSARY OF THE IMPLEMENTATION OF PL 94-142: AN IDEA AHEAD OF ITS TIME

Historical Background

During the 20th century, there has been slow, steady progression of legislation and program development acknowledging the citizenship and fundamental rights of individuals with disabilities. The timeline in Tables 1 and 2 delineates events that have had a profound effect on the current configuration of services for children with disabilities. In 1935, the passage of Title V of the Social Security Act created the Crippled Children’s Programs in each state to provide services for children suffering from disabling conditions such as infantile paralysis. Ten years later, a Section for Exceptional Children was established within the US Office of Education – again including the importance of a planned approach to the needs of a special population of children.

In the 1960s, the first President’s Panel on Mental Retardation proposed a new conceptualization of mental retardation and developmental disabilities. Rather than making the primary focus a view of what people cannot do, the panel urged celebration of and responsiveness to what children with disabilities can do. Furthermore, the panel responded to the

fact that both parents and professional advocates demanded that a more systematic response to the educational and functional needs of children with disabilities ought to be implemented.^{2,3}

In 1972, two critically important lawsuits paved the way for educational reform for children with disabilities. *Pennsylvania Association for Retarded Citizens (PARC) v Pennsylvania* established the precedent that children with disabilities should not be excluded from public education.⁴ In *Mills v the Board of Education of the District of Columbia*, the court ruled that the school systems that placed children in segregated placements might be using “special education” as a process for *de facto* segregation.⁵ The court in *Mills* also ordered that schools must provide adequate education to all children even if they did not have sufficient funds to do so. In response to community pressure and to these two cases, states began to create and revise their special education statutes. While in the past, special education designations had been used to exclude children and adolescents from school opportunities, some state laws were written to encourage the schools to include children with disabilities in all activities offered to children without disabilities.

The watershed event occurred in 1975, when the U. S. Congress passed P.L. 94-142 by an overwhelming majority. Subsequent amendments and refinements have maintained the law’s core tenets and extended its reach to infants, toddlers, and preschoolers with disabilities. States must provide a Free Appropriate Public Education (FAPE) to all children no matter what disabling condition might be present. The education should take place in the “least restrictive environment.” This is achieved by (1) identification of all children with special needs; (2) evaluation and the preparation of a detailed plan; (3) implementation of educational and related services; and (4) maintenance of the child’s rights through “due process.” We outline here the major provisions of IDEA in its current form.

Provisions of the Individuals with Disabilities Education Act

1) Identification and referral

Children can be identified and referred for early intervention services as early as birth. Once a child is diagnosed as having a functionally relevant health concern (such as congenital anomalies, cerebral palsy or hearing loss) or is noted to have developmental delays, s/he is eligible for early intervention under IDEA. Parents, physicians, or childcare providers can refer children for a team evaluation and subsequent service provision.⁶ It is important to note that “disability” is defined state by state; moreover, the referral is directed to a specific agency in each state. In some states, the lead agency is the Department of Public Health, in others, it is the Department of Education, and other states place the program elsewhere; also, the states can change this structure at any time.⁷ There is no federal mandate as to which should be the lead agency (for birth to three programs), and those who refer children and their families need to be aware of the administrative details in their state.⁸

All identification of children who have passed their third birthday is handled by each state’s Department of Education.⁹ All school systems are required to have established formal preschool identification procedures to detect developmental concerns as they emerge. These

include CHILD FIND programs, 1-800-numbers, and kindergarten screening programs. The identification process does not end at the kindergarten door. Some children acquire health concerns (e.g. trauma, infection), which place them in need of special education. In addition, some educationally related problems do not manifest themselves until the children have been challenged by schoolwork. Subtle developmental difficulties may show up as difficult behaviors (e.g., hyperactivity, acting out, withdrawal, poor appetite, enuresis, encopresis, drug and alcohol use, truancy, delinquency). Children and adolescents can be identified as in need of special education at any time during their educational career. In fact, older students occasionally refer themselves for services.

2) Evaluation

Every child involved in special education must have an Individualized Educational Program (IEP) that includes information on the child's current performance, annual goals, and a description of planned services with objective criteria for measuring the child's progress on at least an annual basis. It is a requirement that a parent should be invited to contribute to the formation of the IEP. In addition, the information in the IEP must be based on the assessment of a multidisciplinary team that must include a specialist in education, and can include a psychologist, a speech and language pathologist, a physical therapist, and an occupational therapist, and a physician. Evaluation by child health professionals as part of the IEP is particularly relevant for children with complex medical conditions; children who are receiving nursing care at school; those who are on medications; and those who have substantial mental health concerns. The actual composition of the team should be tailored to the questions that have arisen for the student. In carrying out the evaluations, school systems must use a variety of assessments, including appropriate standardized materials that are technically sound and address educational, behavioral, physical, and developmental concerns. The assessments must be free of racial and cultural bias and administered in the child's own language or mode of communication (e.g., sign) by personnel who are appropriately trained and experienced in the use of the particular assessments.

Each required evaluation for children from birth to three results in an Individualized Family Service Plan (IFSP). Since family issues are often paramount during the early years, the IFSP explicitly calls for an assessment of the family's needs. The IFSP outlines the content of the service package, the quantity of services to be delivered, the venue (home- or center-based), and the personnel who will be working with the child and family. Because the children often have multiple needs, the intervention plan may involve training of family members or other professionals to deliver services so that there are a manageable number of providers interacting with the child.

3) Services (Early Intervention, Special Education, Related Services)

For young children, early intervention services are delivered by a variety of personnel and in a variety of venues as designated through the IFSP. The services include home and center based interventions by physical and occupational therapists as well as speech and language therapy, deaf and blind education, parent training, social work services, etc. Increasingly, early intervention programs are providing intervention for children who manifest problematic behavior

either as a primary concern or secondary to another disorder (e.g. developmental delay, deafness).

Special education for preschoolers, school aged children and adolescents encompass activities that enhance the forward development of every child. For severely affected individuals, this may be improvement in daily living skills (ADLs) such as eating, ambulation, transfers, bathing, toileting, and communicating basic needs. For children with complex learning styles, it may be noticing the subtleties of a non-verbal learning disability and providing a child with the appropriate strategies to deal with their inability to understand simple spatial relationships.

To meet the complex and varied learning needs, IDEA has supported the development of innovative practices through its discretionary programs of research and technical assistance. Examples of research-based innovations include the development of various communication systems for non-verbal children, computers that read text for blind children, early behavioral interventions for children with autism, and teaching strategies that support children with mental retardation in inclusive settings. Innovations are constantly being developed that can improve educational and developmental opportunities for children with disabilities. A helpful website which contains links to many of the research and development efforts in special education is www.ideapractices.org.

Services for children with disabilities are to take place in the *least restrictive environment* (LRE). School systems are required to look carefully at the school placements of the children to assure that the children have full access to the regular curriculum. “Each public agency shall ensure (1) that to the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are nondisabled; and (2) that special classes, separate schooling or other removal of children with disabilities from the regular educational environment occurs only if the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.”⁹

For example, if a child can learn well in a regular classroom and the only thing keeping him out is the width of his wheelchair, then the school is obligated to make physical accommodations to allow the child into that classroom. While in the majority of cases, the least restrictive environment for a child is the regular classroom, for some children their learning may well be enhanced by a different arrangement. For instance, LRE embraces situations in which a child with severe emotional disorder might be, in fact, more appropriately educated in a separate environment with specially trained teachers rather than in an open classroom with substantial risks and challenges. Most importantly, regardless of environment, the child must have access to the general education curriculum, as appropriate to his/her needs.

IDEA addresses barriers to access to education through the provision of special education and related services. The law defines special education as “specially designed instruction, at no cost to parents, to meet the unique needs of a child with a disability.”⁹ Related services are defined as “transportation, and such developmental, corrective, and other support services as may be required to assist a child with a disability to benefit from special education.” Such

services may include speech and audiology services, psychological services, physical and occupational therapy, recreation, social work, school health services, counseling and medical services for diagnostic and evaluation purposes. These services can be provided only if they are related to the child's educational needs.⁹ For instance, a child may get occupational therapy to help her to use a pencil or pen correctly so that she may have access to what is being taught in a classroom. A blind child may receive orientation and mobility services to help him get to his classes independently.

4) Due Process

The IDEA legislation assures that parents must be involved in all decisions regarding education plans, placement, and services for the child with disabilities.⁹ Under IDEA, the parents of children with special needs have the right to dispute the plan that is developed for their child and request further evaluation and/or the implementation of a different set of services. Due process provisions are carefully delineated. First, parents are full members of the IEP team and have early, meaningful input into their child's program. Further, parents have to approve the program being offered their child. Families sometimes choose to obtain independent assessments of the student before agreeing to an educational plan. Parents may dispute the school district's offer through an impartial due process hearing. The hearing process is designed to determine the most appropriate placement for the child. The decisions of hearing officers can be further challenged in court or the parents can choose to use the services of a state-appointed mediator who seeks to reach a mutually acceptable agreement between the parent and the district. Throughout the process, the child generally stays in his or her existing placement.

Parents have the right to timeliness in the proceedings, open disclosure of all assessments that may influence the program recommendations and proper education on the issues at hand. These due process rights have provided a level of educational assurance to children with disabilities – a level which is actually above that which is accorded to children without disabilities. Many families have used these mechanisms to protect the rights of their children. A few have even fought their cases as far as the U.S. Supreme Court.

MAJOR ACCOMPLISHMENTS AND ONGOING CHALLENGES FOR CHILDREN WITH DISABILITIES UNDER IDEA

Since the initial implementation of the special education law in 1976, there has been real progress on a number of fronts for children and adolescents with disabilities. These accomplishments are:

Increase in the numbers of children receiving special education services

In 1966, an estimated 1.2 to 1.8 million children were enrolled in special educational programs for exceptional children.¹⁰ As of November 1999, over 5.5 million children (aged 6-21) are enrolled in special education (see Figure 1).¹¹ In addition, nearly 600,000 children (ages 3-5) are being served through a variety of home and center based early intervention programs.¹¹

Actual federal expenditures on special education have increased from less than \$252 million in 1977 to almost \$5 billion in 2000 (see Figure 2). Unfortunately, the actual federal appropriations have lagged far behind the projected supports that the original framers of the program intended.¹²

Greater precision in the diagnosis of children's disabilities

Disability designations have changed appreciably. The diagnosis of "learning disability" has had a dramatic three-fold increase, in large part because families, teachers, and physicians now have a greater awareness of the children's varied learning styles.¹³ The diagnosis of "mental retardation" has declined from 820,290 children in 1977 to 611,076 in 1999.^{11,14} Some of the decline is due to the availability of prenatal diagnosis and to screening programs for the early detection of disorders such as PKU and hypothyroidism. However, most observers believe that previously there was serious over-identification of children with environmentally induced delays.⁸ These children's "retardation" was perpetuated and even exacerbated by the poor schooling they received in segregated, low stimulation classrooms.¹⁵

Curricular innovation for children with different learning styles

Intensive educational strategies for elementary school students experiencing difficulty learning to read have been developed, based on research on dyslexia conducted by the NIH. Various types of technologies have been developed to assist students with disabilities in school, ranging from computers that can read print to simplified spell checks. In addition, there are many simple changes that can be implemented in the school environment and structure which have been shown to be beneficial to children with special learning needs.¹⁶

Access for children with physical and sensory impairments

In the 1977-78 school year, only 41% of children with orthopedic disabilities were being educated in the regular classroom.¹⁴ In 1997-98, 68% of children with orthopedic disabilities were in regular placements (see Figure 4).¹¹ Similarly, the gains for integration of children with hearing and vision impairments have also been dramatic since the start of implementation of P.L. 94-142: In 1977-78, only 48% of children with sensory impairments were in regular classrooms and by 1998 this percentage had risen to 60%.^{11,14} Architectural modifications (as required by the American Disabilities Act), advances in hearing aides and FM transmitters, improved use of new visual technologies, and partnership of educational and health professionals account for much of the improved access.

Major decrease in the institutional placement of children with mental retardation

In 1970, nearly 90,000 children were institutionalized, often in overcrowded, poorly staffed facilities. Some of these children never saw their families nor did they have any access to educational opportunities.¹⁷ By 1995, all but 3500 children were able to transition out of such

settings. Of course, this is one of the shining achievements within special education and the wonderful impact it has had for the children, their families, and the larger society cannot be overstated. Community resources have been devised to assist families and allow them to care for their children at home and in their own neighborhoods. In addition, there have been real changes in the facilities that continue to operate, including improvements in staff (and staff training), improved physical plants, and especially, increased family/community involvement and oversight. Due to the shifts in perspective of care for those with cognitive disabilities (and with increasing technological supports), the population of children who remain in long-term care facilities has become increasingly medically complicated. This will make the task of those who continue to help transition these children to their families and communities increasingly difficult.

Challenges that remain under IDEA

Notwithstanding all of these accomplishments, significant challenges remain.¹⁸ Despite new knowledge about how children with disabilities can learn, many children with learning problems have not benefited from the new special education techniques and the long-term outcomes for children with learning disabilities have been mixed. A recent study by the National Council on Disability found significant non-compliance with IDEA in most states, and there remain substantial socioeconomic and racial disparities in access to high quality special education services.¹⁹ Children with mental retardation (MR) are now living in communities and going to school with their brothers and sisters. However, they are still rarely accommodated within the regular classroom setting. Figure 3 demonstrates that only 12.6 percent of classified with MR were receiving their education in full time regular classrooms in the 1997-1998 school year. While this is a doubling from the figure of 5.9 percent in the 1988-1989 school year, the small number indicates that there continues to be a need for more specialized placements for children with complex developmental concerns.¹¹

Schools are experiencing ever increasing difficulty in dealing with the challenges they face in handling children with emotional and behavioral disorders, including Attention Deficit Hyperactivity Disorder (ADHD). The number of children with emotional disorders has doubled since 1976. Moreover, in 1999, the special education regulations were modified to allow services for children with ADHD under the classification "Other Health Impaired." Unfortunately, the response to children with emotional and behavioral needs has been constrained by the lack of adequate resources to address many of the children's serious problems. In some states, the situation has reached crisis proportions. For example, on October 25, 1994, the State of Hawaii acknowledged to the federal district court that it had failed to provide necessary services to a class of children who were entitled to, but not receiving special education and related mental health services.²⁰

An area of particular difficulty that has surfaced over the last 10 or so years has been that of "discipline" especially for children with emotional and behavioral problems. Children with emotional problems are obviously a challenge for those who care for them and there remain important clinical questions about the best approaches to their management. The amendments of 1997 included substantial new language about the rights of children with emotional and

behavioral issues with regard to their prompt re-entry into the school setting after an episode of discipline (such as suspension from school).

IMPLICATIONS FOR PEDIATRICIANS

Twenty-five years ago, pediatricians had a limited role with regard to special education. They might be asked to write a note to keep a child with disabilities out of school or to help find an institutional placement for an infant with mental retardation. They would rarely be called upon as part of a team assessing a child's potential. Now, as a result of the past quarter century of experience, there are clear roles and expectations for pediatricians to serve as active members in the special education process. Using four illustrative cases, we will discuss a number of these activities.

Case One: "Why isn't Sarah talking?"

Sarah's parents bring her to your office for her eighteen-month well-child check-up with a long list of questions. However, during the screening questions you find out that she does not use any words yet; she has become especially adept at making her needs known through a combination of gestures, crying, and occasional bursts of verbal output (all vowel sounds). When you ask her parents about her hearing, they have not had any concerns. When you ask about family history, they report that they know of no one in the family with hearing problems.

Early detection of functional disability is a key role for pediatricians. From the very first encounter a physician has with a child, there are chances to discover developmentally relevant conditions such as sensory deficits, metabolic abnormalities, acute and chronic infectious disease states.

This case illustrates the value of a systematic approach to screening for developmentally relevant material. Sarah's parents have questions about her, but it is through the formal screening questions that a concerning pattern emerges. Increasingly, pediatricians are finding the value of such approaches to developmental screening and monitoring.²¹ At each office visit, it is important for the child health practitioner to probe for those underlying conditions that may put the child at risk for later developmental delay and educational risk. Such an approach is outlined in detail in *Bright Futures: National Guidelines for Health Promotion*.²² Many screening devices are now available to pediatricians.^{23,24} There are also a number of web-based and electronic encounter forms that facilitate the screening and compiling of developmental information.

Developmental monitoring should begin at birth. Risk of developmental delay is associated with premature birth, prenatal exposure to infectious agents, toxins and drugs, birth trauma and congenital anomalies. Special attention to the developmental trajectories of children in these risk categories and prompt referral to early intervention programs can be facilitated by maintaining risk registries or by providing additional early visits for children who meet these criteria.

Increasingly, many states' Departments of Public Health are improving the early detection of developmental disability through newborn screening mechanisms.²⁵ Currently, all states screen newborns for PKU and hyperthyroidism. Many states have increased their panels of metabolic tests (47 states screen for galactosemia, 22 biotinidase, 19 maple sugar urine disease, and 13 homocystinuria), so that it is now possible to detect a wide variety of amino acid and organic acid disorders. Increasing numbers of states have enacted legislative initiatives with the goal of universal newborn hearing screening. As a result, families may learn of a child's deafness right at birth and their pediatrician may be able to facilitate early intervention almost directly out of the newborn nursery.²⁵

Sarah's case points to the need for repetitive probing about developmentally relevant concerns. For instance, newborn screening will miss the 10% of acquired and progressive sensorineural hearing losses in children that cannot be detected at birth.²⁶ Moreover, conductive hearing loss can also be a serious concern for young children. Because such hearing loss can appear at any time and then fluctuate, it is a good practice for offices to maintain monitoring programs for hearing. Familial concern about hearing loss at any time warrants careful follow-up and assessment by an audiologist skilled in pediatric hearing testing.

If Sarah does turn out to have a hearing loss, in addition to the medical management, the child health professional now has the responsibility of directing her family to appropriate audiological and speech and language treatment for the child through the state's early intervention program. Recent data on the effectiveness of early intervention for children with hearing problems strongly indicate that prompt detection can significantly improve a child's ultimate language, academic, and life performance.^{13,27}

Sarah's case has other implications. The pediatrician may pursue the hearing testing and be reassured that the auditory acuity is fine. At the next visit, developmental monitoring is essential to determine whether language is progressing.²¹ If it is not, the child may have a significant expressive or receptive language problem that deserves in depth investigation by a speech and language pathologist. Children with early language disability can be helped enormously by early intervention.

Case Two: "Why can't T.J. pay attention?"

T. J. is a 7-year-old boy who has been in your care since birth. He has been healthy throughout his life and met all milestones appropriately. Now in second grade, his parents have brought him to your office because they have received several reports from his teachers that he is "hyper."

Pediatricians commonly become involved with special education regarding the assessment and treatment of children for Attention Deficit Hyperactivity Disorder (ADHD). There is an extensive literature about this diagnosis and the treatments offered for it, both conventional and alternative.^{28,29,30} The first task of the pediatrician confronted with the case of T. J. would be to take a careful history, specifically highlighting aspects that are included in the DSM-IV criteria for diagnosis of ADHD. Additionally, the clinician must determine that there

are no other medical causes for difficult behaviors; these include hypo- or hyperthyroidism, lead intoxication, anemia, hearing or vision impairments, and other treatable conditions.

Children with ADHD are preferably assessed with behavior rating scales, and these are best when completed by different observers in different settings.^{28,31} Therefore, there will need to be communication between T. J.'s pediatrician and the school system. The differences between the cultures of health care and education can either prove rewarding or frustrating, or both. Therefore, it can be critical to establish an effective parent-clinician-educator partnership to ensure that relevant information can be obtained in a timely and efficient manner.

If these assessments lead to the diagnosis of ADHD, the next task for the pediatrician is to help the family to understand this diagnosis and its implications: medical, social, and academic.³² Finally, the clinician becomes involved in the formulation and implementation of appropriate therapies for the child, including behavioral modification strategies (often including appropriate recreational activities), educational supports, and medications. Each of these will require further involvement of T. J.'s parents with the school to ensure that they are accomplished appropriately, and often the support of their pediatrician can prove crucial. Like all children with disabilities, not all children with ADHD qualify for IDEA services. A significant number of these children simply receive accommodations under Section 504 of the Rehabilitation Act.

Fortunately, straightforward systems of involvement can be set up and the process does not need to be laborious or complicated. Also, few educators will be ignorant to the need for support for children with this condition, and systems for both communication with doctors and dispensing of medications are often already in place. Certainly, if a pediatrician develops a good relationship with her local school district through the management of children diagnosed ADHD, the care of children with more complicated medical and educational needs will likely be easier.

Case Three: "How can we prevent Jamie from failing?"

Jamie is a 13-year-old teenager who has been in your practice since birth. She has been healthy throughout her life and this is the first urgent care appointment that her family has made since her last ear infection 10 years ago. Her mother explains (with Jamie in the room) that her grades have been falling ever since transferring to middle school, from B/C's to D/F's. Her parents have just had a meeting with the staff of the school who expressed concern that Jamie will not be able to make the transition to High School and that she should be retained in eighth grade for a second year. Jamie is strongly against this option. Her family is now in your office for advice on this problem.

Clinicians who are assessing academic problems in children who had previously been "doing OK" are confronted with a broad and diverse differential diagnosis list. This problem of seemingly endless options is similar to presentations of abdominal pain or fever of unknown origin. Therefore, the clinicians who are confronted with this common problem must have a theoretic framework in order to address the work-up and treatment systematically. School problems stem from a variety of different etiologic causes and may, in fact, have more than one

cause: primary learning disabilities, depression or other mental health diagnoses, family strife (including the extreme cases of physical or sexual abuse), abuse of alcohol or other illicit substances, both acute and chronic medical diagnoses, and disruption of relationships. Each must be considered in the assessment of a child presenting like Jamie.

Although most children with a primary learning disorder present earlier than middle school, it is unfortunately too common that some students' difficulties are ignored or ascribed to "laziness" for many years. This delay in diagnosis can be extremely damaging and lead to additional, secondary problems (such as frustration with school, diminished self-esteem, and even depression). Determining the specifics regarding the actual academic difficulties which Jamie is having will be crucial to the process of assessment. A first step would be to take a detailed history from both the parents and the student; usually this is best done with separate interviews. In addition, school records can be invaluable resources in the gathering of the data of the investigation. In this case, an IEP evaluation by the school district should be requested, if it has not yet occurred. There are many different learning disability phenotypes, so it is important to assure that the child has had the benefit of a detailed assessment of the many facets of learning. An examination of a student's learning styles and general competencies can be performed in the office by a child psychologist, educational specialist, or a developmental pediatrician. These direct observations allow the clinician to have a first-hand look at the student's academic skills.³³ This can be particularly important in cases where there is disagreement between schools and family about the student's abilities, which is not uncommon.

During this assessment of her learning problems, it is crucial for the medical team not to overlook potential physiologic causes for her poor performance. These include new diagnosis as well as old ones that have now resurfaced as a problem. Of course, it is also important to remember to think about sex, drugs, abuse, and instances of family disruption (e.g., divorce, frequent relocation, and financial distress). Although these are not the usual causes for school problems, difficulties in academics may be the first signs that a clinician notes regarding a problem that is otherwise hidden.

Finally, the idea that a child should simply repeat a grade, usually with the same teacher and materials, is rarely a good one. If a child failed on the first try, she is unlikely to improve the second time, especially now that she has been removed from her cohort of classmates and likely suffers humiliation. A better course by far is to determine the reasons for her failures and then to address them. It is easy for schools to suggest that they are "getting tough" and "raising standards," but it is much more important that they address the real needs of the real children who are struggling to succeed.

Case Four: “What are Jeffrey’s rights?”

Jeffrey is a 12-year-old boy who sustained a transection of his spinal cord at C1-C2 after a diving accident. After eighteen months of intensive rehabilitation, he is able to direct his wheelchair and use a specially modified computer, but he is still completely ventilator-dependent and requires constant nursing care. Before the accident, he was an honor roll student and a top athlete on several teams. Now, he and his family are attempting to re-enroll him in the local public school. His parents have asked for your support in arranging his transition back to school.

As a result of IDEA, children with physical disabilities and nursing needs cannot be excluded from school. Two U.S. Supreme Court cases have upheld the right of children with complex health needs to receive special education and related services.^{34,35} While children have the legal right to attend school, it is incumbent on health care providers to assure that the nursing services these children receive are of high quality and that the individuals who are providing those services are adequately trained and monitored.

Few cases will be as complex as the one presented above. Nonetheless, in busy practices, most pediatricians will be caring for patients who have some level of assistance by medical technology (e.g., gastrostomy, tracheotomy, indwelling IV catheter, bladder catheterization, etc.). When it comes time for these children to attend school, the role of the pediatrician is central in ensuring that the plan set out for the child is thoughtful and practical, concerning his/her medical and nursing needs.

Entrance to school and transitions from one type of school setting to another present important opportunities for physicians to assure that children with special health care needs are adequately supported. School administrators need to know the child’s condition. They want information about any safety concerns either for the child or for others around him. Most often communication to the school can be most reassuring and can reduce the level of anxiety that the school feels. Often children with special health care needs will require accommodations in school. Physician input into the discussions with the school can often be very helpful in procuring the proper renovations and or equipment. If a child has a rare condition or requires the school to provide a particular procedure such as clean intermittent catheterization, tube feeding, or respiratory care, the school may need to hire and/or train new staff. School officials will turn to pediatric providers for help with this process (see Figure 6).³⁶

Beyond school entrance and transitions, pediatricians who are caring for children with complex medical needs and particularly those who are assisted by medical technology should concentrate at least one visit a year on discussing with the child’s parents what is happening in school. If the child is receiving special education services and has an educational plan in place (an IEP), it is very valuable for the child’s health care provider to participate in the preparation of a companion document or Individualized Health Plan (IHP). Such a document should include information on the following topics: the child’s diagnosis, important personnel with contact information. The child’s special health care needs, baseline status, medications, diet, transportation needs, procedures and equipment, child-specific techniques and helpful hints, special considerations and precautions, emergency information and emergency plan. This health care plan should be agreed to and signed by the child’s parents or guardian, the child if

appropriate, a school administrative representative and the physician. A doctor's order sheet and parent authorization for specialized health care should accompany the IHP. This systematic approach has been developed through Project School Care and used in many communities across the United States. Published guidelines for the care of children with complex medical needs are available.³⁷

BEING YOUR PATIENT'S ADVOCATE

Through IDEA, pediatricians can advocate for their patients in a number of ways: through actions on behalf of individual children or families (a frequent avenue); through actions in a local region (i.e., on the school board or town council); or at the state and national level (e.g., by writing letters or giving testimony).

When children enter early intervention, the full extent of their health and developmental profile may still not be thoroughly delineated or understood.³⁸ During the period of early intervention, additional components of disability are often discovered or elucidated. Physicians who are tied into the process can both contribute to and benefit from this process. For school age children pediatricians can often make or break the child's chances of getting appropriate special education services. Pediatricians who take the care to learn the specific language of the special education eligibility determinations can be extremely helpful to families. Failure to use the appropriate terminology, on the other hand, may result in poor communication with the school and lack of services for a given child. It is wise for pediatricians to keep up to date with the state special education procedures and nuances.

Pediatricians who keep abreast of the special education system developments are in an excellent position to alert parents to their entitlements and to help them to navigate through the complex and lengthy process. Specific assistance can be offered by: (1) ensuring that the family contacts the local special education office in writing as soon as a difficulty is suspected; (2) requesting a copy of the reports generated by each separate assessment (both to maintain a complete copy in the medical record of the child and to encourage timeliness in reporting); and (3) reviewing the final IEP with the family when it has been produced (but before it has been signed by the family). Too often, parents feel intimidated during large meetings with school personnel. Occasionally, it may be important for the physician to send a letter to the assessment team or even to attend the meeting with the parents. Most school districts are very interested in the involvement of a child's doctor and this type of advocacy for the child can have a large impact on the ultimate substance of the IEP.

Throughout the 25 years since the first implementation of the federal special education legislation, localities and states have struggled with funding special education services. As a result, there have been periods in almost every state of retrenchment as the expense of providing services has increased. One significant challenge comes from the unfulfilled promise of federal sharing in the funding formula (see Figure 2). As a result, the funding issue emerges periodically as a congressional debate.

Whenever there is a reauthorization of legislation as far reaching as IDEA, it is critical that professionals join with parents in advocating to maintain the successful portions of the laws and to improve those areas that remain weak. IDEA is scheduled for reauthorization in this Congress.³⁹ It will be critically important that pediatricians speak up both singly and collectively so that no ground is lost for children with disabilities and new gains are made for children with mental health problems and children who suffer the double disadvantage of living in poverty and having a disabling condition.

CONCLUSION

“Wisdom, and knowledge, as well as virtue, diffused generally among the body of the people, being necessary for the preservation of their rights and liberties; and as these depend on spreading the opportunities and advantages of education in the various parts of the country, and among the different orders of the people, it shall be the duty of legislators and magistrates, in all future periods of this Commonwealth, to cherish the interests of literature and the sciences, and all seminaries of them; . . . to countenance and inculcate the principles of humanity and general benevolence, public and private charity, industry and frugality, honesty and punctuality in their dealings; sincerity, good humour, and all social affections, and generous sentiments among the people.”

A CONSTITUTION OR FRAME OF GOVERNMENT, Agreed upon by the Delegates of the People of the STATE OF MASSACHUSETTS-BAY, March 1780, Chapter V, Section II. “The Encouragement of Literature, etc.”

At the present time, when budgets are tight and it seems that too often education is not seen as a high priority for state governments, it is good to remember our history as a country. The original framers of democracy in America, including John Adams who was one of the framers of the Massachusetts Constitution (which served as a model for the U.S. Constitution), realized that in order for democracy to work, the population must be well educated. For, to preserve their “rights and liberties” the citizens needed “wisdom, and knowledge, as well as virtue.” In addition, they foresaw the need to “[spread] the opportunities and advantages of education . . . among the different orders of the people.” In other words, one of the bedrock foundations to the American experience was the universality of a quality education.

It is in this light that the movement for quality special education must be seen. It is not a recently discovered right that sprang from the idealism of the 1960s, but rather a basic right that had not yet been fully realized (like so many of the principles of the founding patriots). Special education is part of the enlightened understanding of our culture, which realizes that it benefits the group if ALL of its individuals are empowered by a full education. This insight stems from the simple fact that if all are educated, then there is no “wasted talent.”

With this in mind, we must continue the movement towards appropriate community inclusion of all our patients, no matter what their condition or disability. It is the duty of all those who interact with children to gain some knowledge of these issues, especially in the ways and time in which they impart the patients whom they serve. Of course, this will not be easy and will require creativity, hard work, and patient persistence.

Table 1: Selected Special Education Legislation

<p>1935</p>	<p><u>Title V of the Social Security Act</u> Established federal responsibility for the well being of children and their mothers; a specific component addressed “Services for Crippled Children.”</p>
<p>1963</p>	<p><u>PL 88-156: Maternal and Child Health and Mental Retardation Planning Amendments</u> A result of a Kennedy presidential commission, this law provided new federal funding for special projects for children with mental retardation (i.e. early screening).</p>
<p>1966</p>	<p><u>PL 89-750: Elementary and Secondary Education Act Amendments of 1966 (Title VI)</u> Added to the Elementary and Secondary Education Act (PL 89-10; 1965) to establish first federal grant program for the education of children with disabilities at the local school level. Also established the Bureau of Education for the Handicapped (BEH).</p>
<p>1970</p>	<p><u>PL 91-230 ESEA Amendments of 1970, including the Education of the Handicapped Act (EHA):</u> This legislation replaced Title VI [see above].</p>
<p>1973</p>	<p><u>PL 93-112: Rehabilitation Act of 1973, Section 504</u> Prohibited federal agencies and any program/activity receiving federal funding from discriminating against someone with a disability.</p>
<p>1975</p>	<p><u>PL 94-142: Education for All Handicapped Children Act</u> Passed in perpetuity by an overwhelming majority. It mandated the FAPE* and was implemented in 1978.</p>
<p>1986</p>	<p><u>PL 99-457 – Education for All Handicapped Children Act Amendments</u> Early intervention – provided appropriate services to infants and toddlers with disabilities and their families</p>
<p>1990</p>	<p><u>PL 101-336: American with Disabilities Act (ADA)</u> National mandate against discrimination based on disability. <u>PL 101-476: Individuals with Disabilities Education Act (IDEA)</u> Reauthorized the EHA, and combined PL 99-457 and PL 94-142.</p>
<p>1997</p>	<p><u>PL 105-17: Amendments to the Individuals with Disabilities Education Act (IDEA)</u> IDEA reauthorized and improved.</p>

Table 2: Special Education Court Cases

1954	<u><i>Brown v. Board of Education of Topeka</i></u> US Supreme Court ruled that an education is a right that must be made available to all on equal terms; in addition, separate facilities were found to be inherently unequal.
1971	<u><i>Pennsylvania Association of Retarded Citizens v. Commonwealth of Pennsylvania</i></u> Ruled that all mentally retarded persons are capable of benefiting from education.
1972	<u><i>Mills v. Board of Education of the District of Columbia</i></u> School systems must educate handicapped students even if their funds are insufficient. In addition, noted significant racial disparities within special education.
1982	<u><i>Board of Education of the Hendrick Hudson Central School District v. Rowley</i></u> School districts must provide appropriate services that allow a student with disabilities to benefit from instruction. They are not required to provide optimal services.
1984	<u><i>Irving Independent School District v. Tatro</i></u> For services perceived as medical but school health related services it created a three prong "bright-line" test: 1) the child must qualify under IDEA for special education, 2) the service is necessary for the child to benefit from special education, 3) the service must be provided by a qualified person other than a physician. Services meeting this test MUST be provided by the school district.
1985	<u><i>Burlington School Committee v. Department of Education</i></u> Tuition reimbursement for private school placement when the public school cannot or has not provided an appropriate IEP or FAPE.
1994	<u><i>Felix Consent Decree</i></u> Required that the Hawaii Departments of Education and Health establish a new system of care by June 30, 2000 for children with disabilities who are eligible for and in need of education and/or mental health services.
1999	<u><i>Cedar Rapids Community School District, Petitioner v. Garret F.</i></u> Affirmed <i>Tatro</i> : services provided by non-physicians, when these services are needed for a child to attend school, are required as related services under IDEA.

*FAPE = Free and Appropriate Public Education

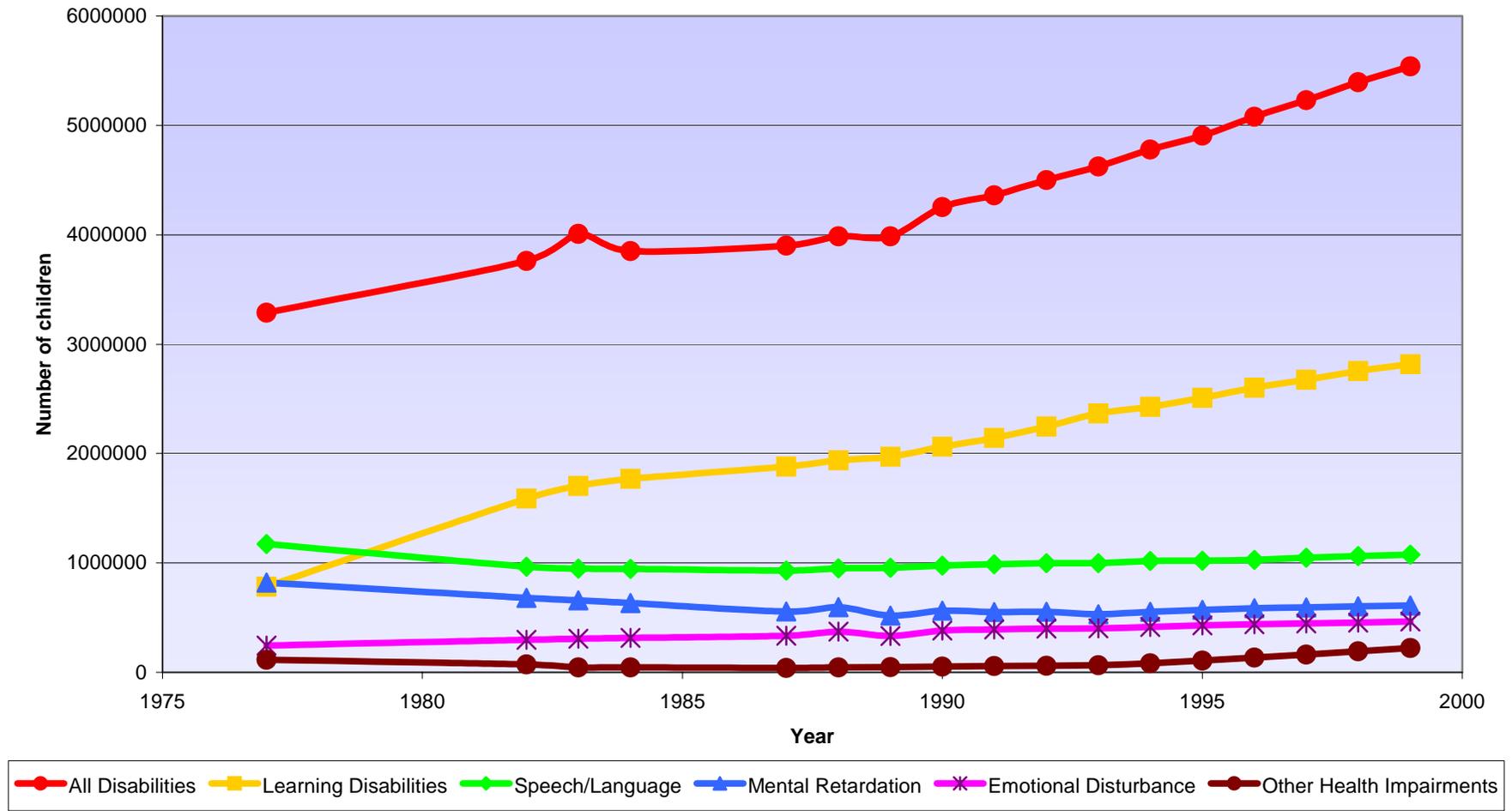
Sources for Tables 1 & 2:

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5. Shonkoff JP, Meisels SJ: Early childhood intervention: The evolution of a concept, in *Handbook of early childhood intervention*. New York, NY, Cambridge University Press, 2000.
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Table 3: Internet resources relating to special education:

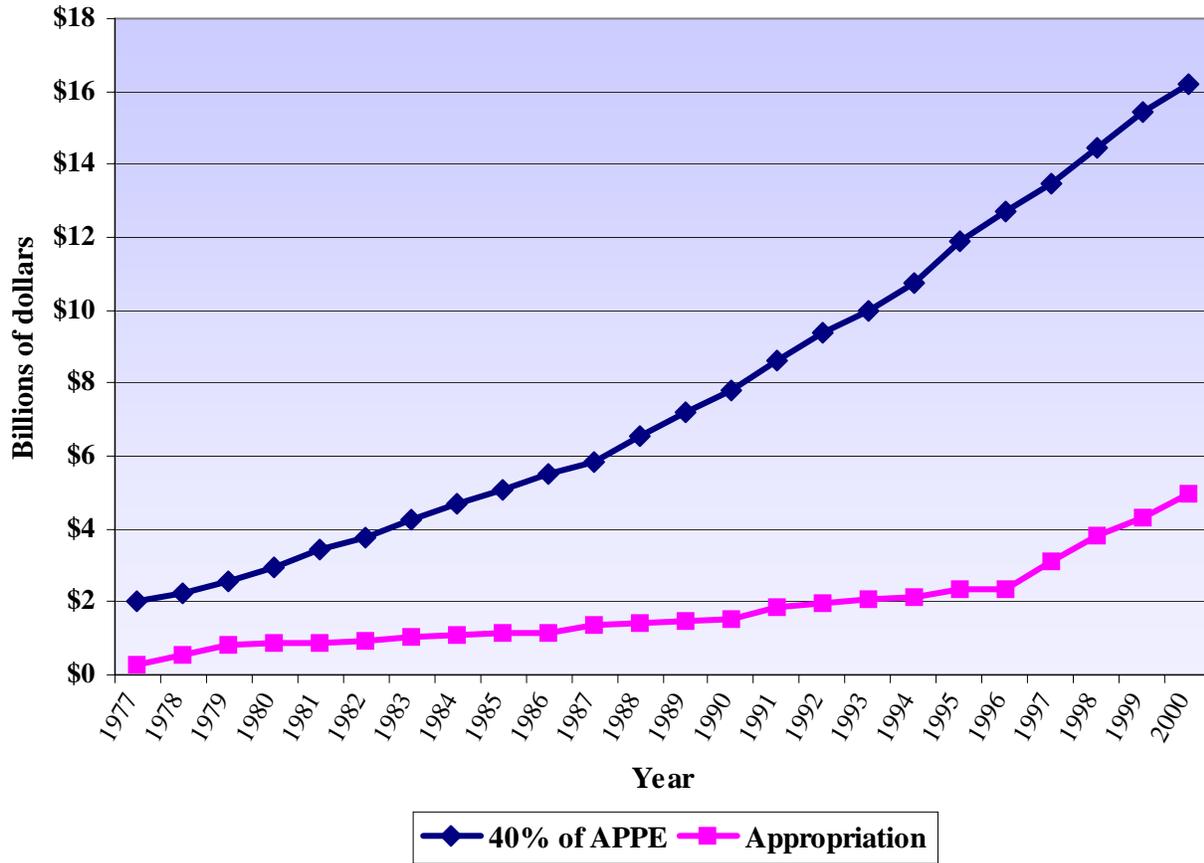
1. www.ideapractices.org/
IDEA Practices Home: This site answers your questions about the Individuals with Disabilities Education Act, keeps you informed about IDEAs That Work, and supports efforts to help ALL children learn, progress, and realize their dreams. *Site design by Education Development Center, Inc. Newton, Massachusetts.*
2. www.ed.gov/offices/OSERS/OSEP/
The Office of Special Education Programs (OSEP) is dedicated to improving results for infants, toddlers, children, and youth with disabilities ages' birth through 21 by providing leadership and financial support to assist states and local districts. Site maintained by the Office of Special Education Programs, Office of Special Education and Rehabilitative Services, U.S. Department of Education
3. www.edexcellence.net/library/special_ed/index.html
Rethinking Special Education for a New Century is a volume of papers examining the past, present and future of special education. It is intended to help lay the groundwork for the 2002 IDEA reauthorization debate. The entire volume is available as a [single PDF document](#). The site is maintained by the Thomas B. Fordham Foundation, Washington, DC.
4. www.aap.org/advocacy/medhome/linksgov.htm
This is the official web site of the AAP, specifically the link to the advocacy section regarding children with special health care needs. It is maintained by the AAP.
5. www.brightfutures.org/
Information on this site is based on published guidelines for health supervision of infants, children, and adolescents. One goal of the Bright Futures Project is to establish a partnership between health professionals and families. This site is designed to be used by both health professionals and families and to help users to better understand the diagnostic process and what to expect during health supervision visits. Issues, concerns, and questions are also addressed. Since its inception in 1990, Bright Futures has been funded by the U.S. Department of Health and Human Services, under the direction of the Maternal and Child Health Bureau.
6. www.sdbp.org/
Formed in 1982, the Society for Developmental and Behavioral Pediatrics (SDBP) is a national, interdisciplinary organization with about 640 members. The site's goal is to improve the health care of infants, children, and adolescents by promoting research and teaching in developmental and behavioral pediatrics.

Figure 1: Number of children (ages 6-21) served by PL 94-142/IDEA, Chapter 1: By Disability
 (From U.S. and territories/outlying areas).



Source: U.S. Department of Education: *To Assure the Free Appropriate Public Education of All Children with Disabilities (IDEA Section 618). Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act.* Washington, DC, Various years (1978-2000).

Figure 2: Special Education Federal Funding: Authorizations vs. Appropriations (Fiscal Year 1977-2000)



Source: US Department of Education – Budget Office: Personal communication. 10/15/2000.

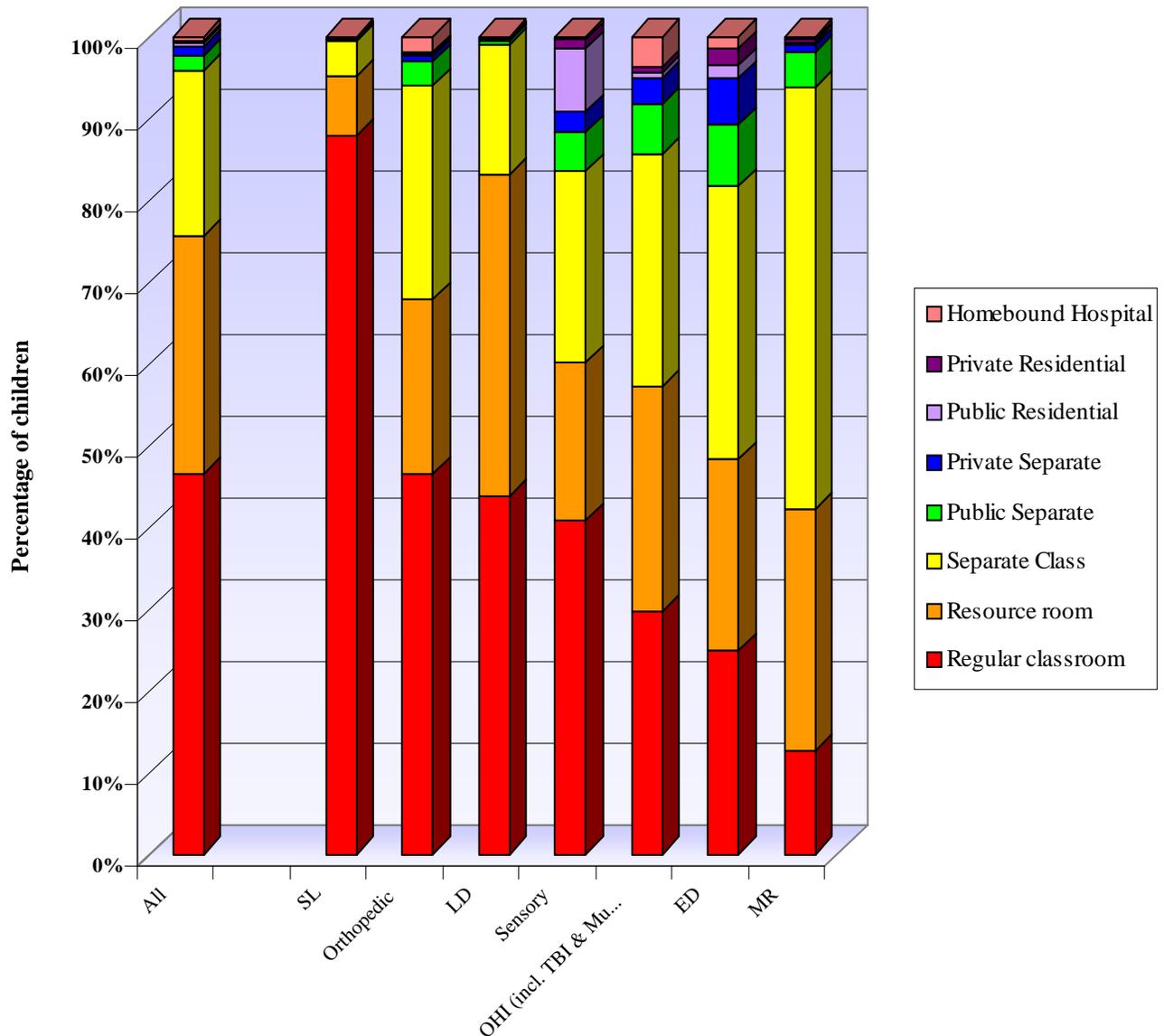
Note: To encourage States to fulfill their obligations, Congress initially authorized funds under a formula that would assist States by paying 12% of the excess cost of education incurred by children with disabilities on a per pupil basis. The federal portion was to increase each year until the federal government would supply 40% of the excess cost, but the appropriations have never reached the initially specified amounts. As a result of the disparity between authorization and appropriation, opponents of federal government involvement in State affairs have frequently referred to special education as “unfunded mandates”.* While the federal funding has remained at a level 12% of excess per pupil expenditure, the actual amount of federal money has increased from \$251,770,000 in 1977 to two billion dollars in 1994 and close to five billion in 2000.** Estimates on the total expenditure on special education (in federal, state, and local dollars) range from \$30.9 billion to \$34.8 billion, much of it being paid by local cities and townships.*** PL 94-142 dictated that States could lose all or part of their federal special education funds if they did not comply with the regulations of the law. Also provisions in Section 504 of the Rehabilitation Act allow the Department of Education to withhold education funds if the proper civil rights assurances for persons with disabilities are not upheld.

* News from Congressman Charles Bass: House Passes Bass Special Education Funding Resolution. June 16, 1998. www.house.gov/bass/pr061698.html.

** U.S. Department of Education – Budget Office: Personal communication. 2000.

*** National Center for Education Statistics – Education Finance Statistics Center: What are we spending on special education in the U.S.? Washington, DC. <http://nces.ed.gov/edfin/faqs/special1.asp>.

Figure 3: Percentage of children (ages 6-21) with disabilities by educational environment*: School year 1997-98



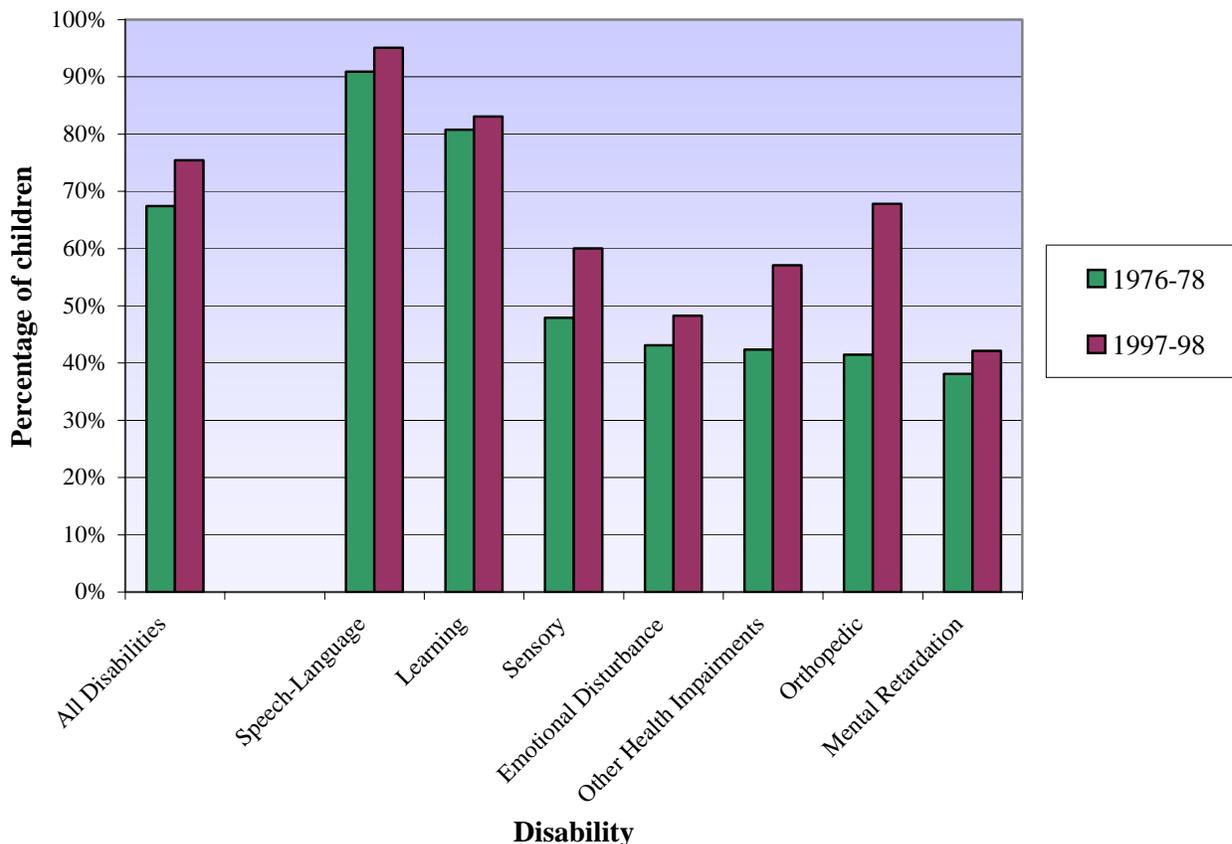
***Notes:** “Beginning in 1989-90, States were instructed to report students in regular class, resource room, and separate class placements based on the percent of time they received services OUTSIDE the regular class (<21, 21-60, and >60, respectively) instead of the percent of time they received special education” (22nd Annual Report, 2000).

All percent values represent the ratio of children with specific disability in the specific environment to the total number of children with this disability.

The category “Sensory” groups the following disability classifications: Visual, Deaf, and Deaf-Blindness. The disability of Autism is not included in this graph.

Source: U.S. Department of Education: To assure the free appropriate public education of all children with disabilities (IDEA Section 618): Twenty-second annual report to Congress on the Implementation of the Individuals with Disabilities Education Act. Washington, DC, 2000.

Figure 4: Percentage of children (ages 6-21) with disabilities in regular (non-separate) classroom: School year 1976-77 vs. 1997-98*



***Note on “Regular (non-separate) classroom”:**

- In 1979, the Annual Report lists the following categories to describe the various educational environments: “Regular classes,” “Separate classes,” “Separate school facilities,” and “Other educational environments.” Only the first category of “Regular Classes” is used in this graph. (1st Annual Report (1979))
- In 2000, the classification expanded from 4 to 8 different educational environment categories (see figure 3 for category breakdown). The categories of “Regular classroom” & “Resource classroom” were combined to parallel the 1979 Regular Classes category. (22nd Annual Report (2000))

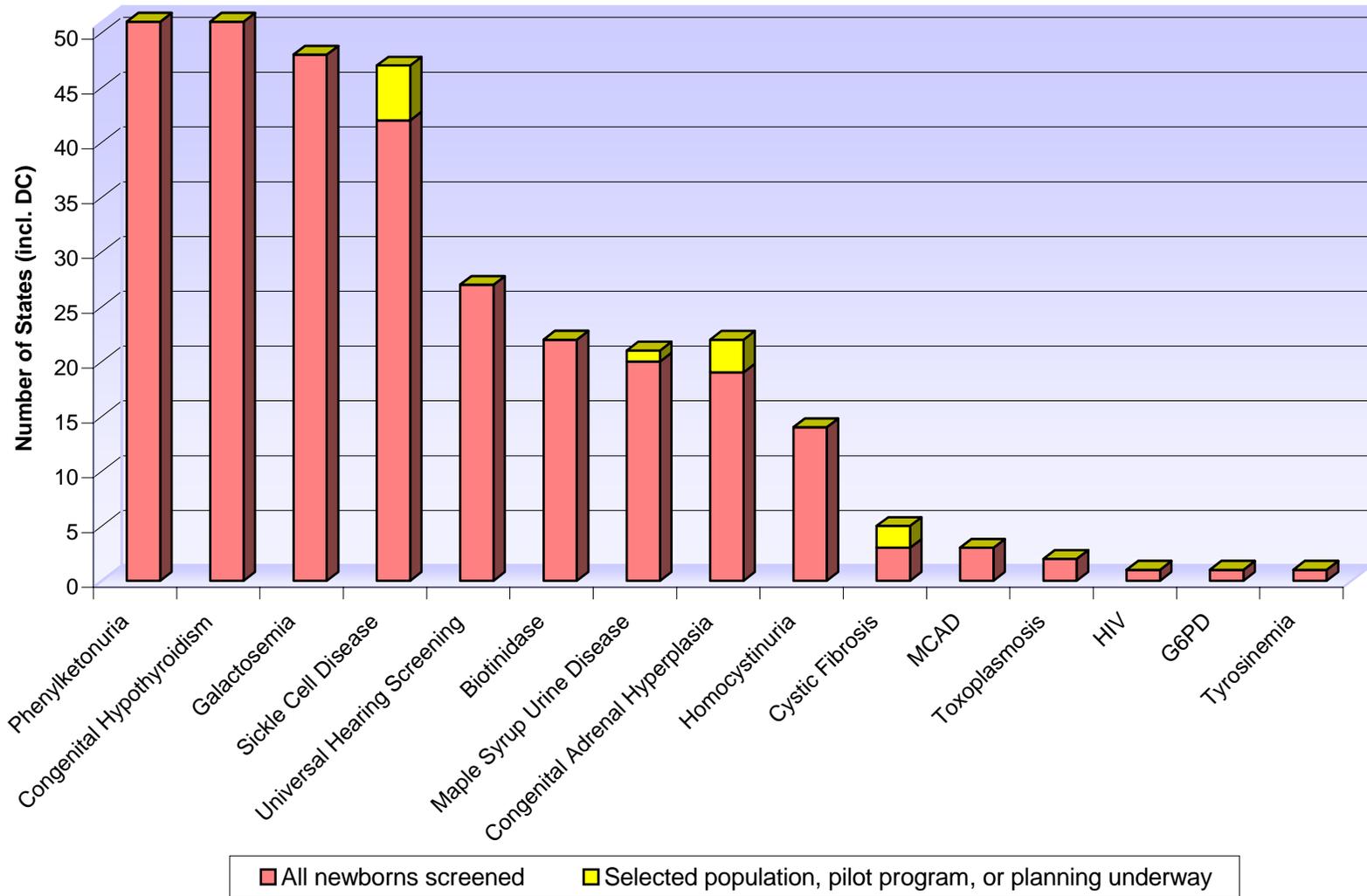
Notes on Disability Classifications:

- “Sensory” classification includes the following disabilities: In 1976-77, “Visual,” “Deaf,” “Deaf/Hard of Hearing,” and “Hard of Hearing.” In 1997-98, this category includes “Visual,” “Hearing,” and “Deaf-Blindness.”
- In both school years, “Other Health Impairments” includes Other Health Impairments, Multiple Disabilities, and Traumatic Brain Injury.
- Autism is not included in this graph.

Sources: U.S. Department of Health, Education, and Welfare – Office of Education: *Progress toward a free appropriate education – A report to Congress on the implementation of Public Law 94-142: The Education for All Handicapped Children Act.* Washington, DC, 1979.

U.S. Department of Education: *To assure the free appropriate public education of all children with disabilities (IDEA Section 618). Twenty-second annual report to Congress on the implementation of the Individuals with Disabilities Education Act.* Washington, DC, 2000.

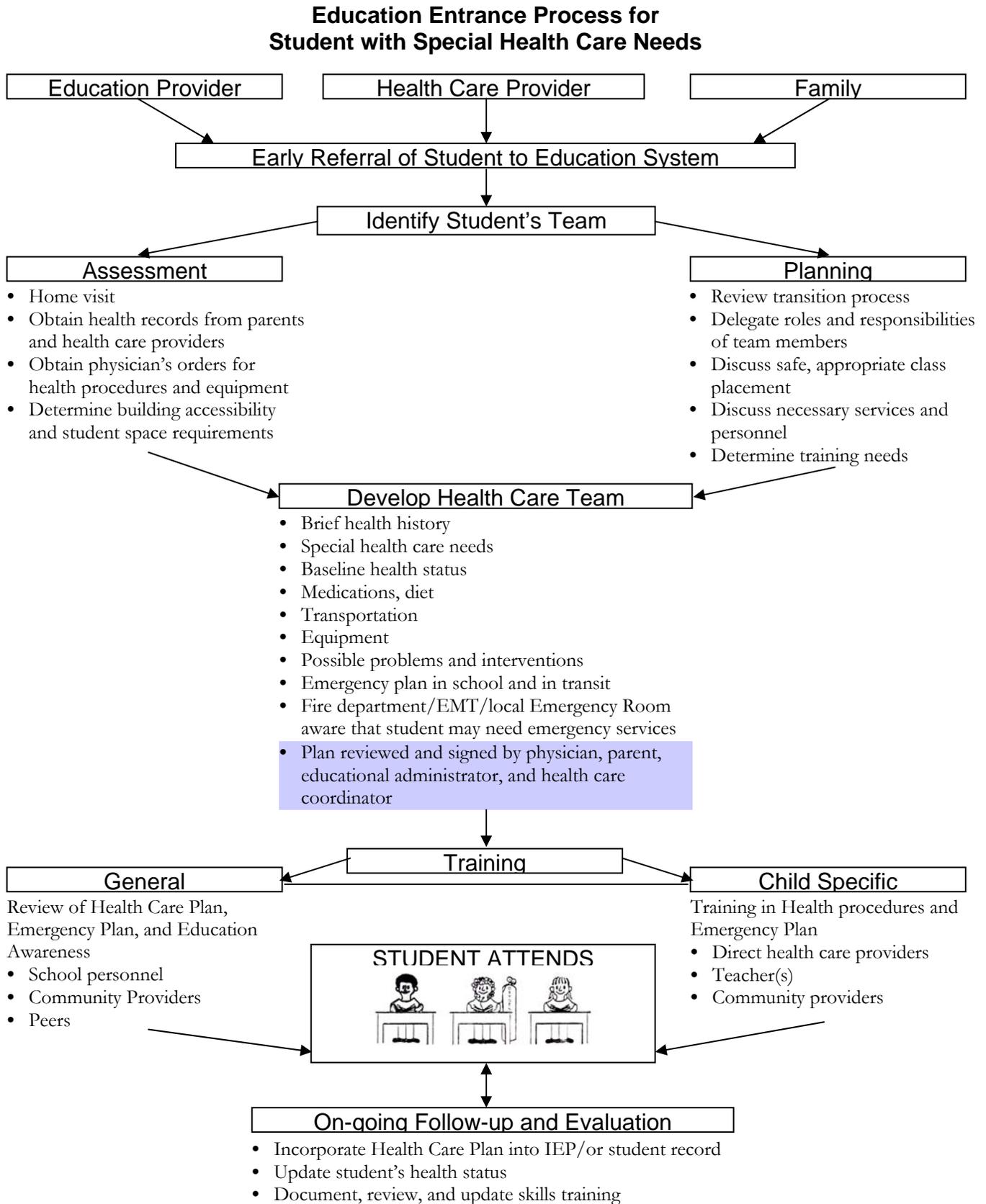
Figure 5: US National Newborn Screening – July 2000



Source: Adapted from AAP Newborn Screening Task Force: Table 1, in *Serving the family from birth to the medical home – Newborn screening: A blueprint for the future; A call for a national agenda on state newborn screening programs. Pediatrics* 2000;106 (suppl):389-427.

Figure 6: Health and Special Education – Project School Care Early Referral System

Source: Palfrey JS: Tool 6.7, in *Community Child Health*. Westport, CT, Praeger Publishing, 1994, p 129.



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