

BIRTH through NEWS

WORKING TOGETHER FOR CHILDREN WITH DISABILITIES

Information for Families and Professionals · volume 2, NUMBER 4

The Spirit of IDEA

By Debbie Burke, Consultant Connecticut Parent Advocacy Center (CPAC)

he Individuals with Disabilities Education Act (IDEA) is the public law considered to be the cornerstone for educational services for children ages 0 to 21 with disabilities. As a parent who works with other parents of children with disabilities, I know how important it is to have an understanding of the law and thought that it would be useful to address the intent, or the spirit of IDEA. And yet, as I began to write, I found myself caught up in the politically correct verbiage of the day, using phrases like "least restrictive environment," "equal opportunity to participate" and "increased parental participation." I realized that I was addressing the letter, but not necessarily the spirit, of the law.

The legal mandates of IDEA are crucial. While it is difficult for any of us to imagine a time when such protections were not in place, only a little more than 25 years ago, public schools were allowed to and did exclude many children with disabilities. Those children who did receive an education were typically segregated into special schools, or, at the very least, separate classrooms. At that time, parents joined together to help change public policy, noting that "separate is not equal" under the U.S. Constitution. In 1975, the federal government passed Public Law 94-142, the

This article is translated into Spanish on page 2. Ver la versión española de este artículo en la página 2.

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COOPERATIVE EXTENSION SYSTEM College of Agriculture and Natural Resources

Education of All Handicapped Children Act, the first legislation to require all states to provide a "free, appropriate, public education" (FAPE) to all children with disabilities. The original law has been refined, amended and renamed, and is now known as IDEA '97. It is what supports the Connecticut Birth to Three System and its Special Education Preschool services. The Individuals with Disabilities Education Act benefits over six million children (ages 0 to 21) nationwide. It is the foundation for all special educational services for children with disabilities, ages birth to 5 and beyond.

No matter what you're building, however, the foundation is only the beginning and, while IDEA is certainly very important, it is not nearly enough. What gives life and substance to programs that serve children with disabilities and their families are the simple yet powerful beliefs that all children are equal, even if they are not the same, and that all children and their families are "worth it." If the law is to mean anything, we must value children for who they are. Parents and professionals must believe that children can and should be able to learn academic and social skills in ways that meet their special needs so they can develop and grow up to be as independent

as possible. They must work together to reach that goal. The Individuals with Disabilities Act is a good and powerful law, but it is how we put our beliefs into action that shapes its true spirit. While that spirit can sometimes be overshadowed by the law's procedural points and its rules and regulations, it is the spirit, coupled with the legal mandates, that will make a difference in the lives of our children and the future not only of public education, but our society in general.

The Connecticut Parent Advocacy Center (CPAC) is a statewide non-profit organization that offers information and support to parents of children with disabilities and the professionals who work with them. The Center is staffed by

parents of children with disabilities who assist other parents in understanding how to participate more effectively in their children's education. You can reach CPAC at (800) 445-2722 or (860) 739-3089 on Monday through Friday.

El espíritu de la Ley de Educación de Minusválidos (la "IDEA")

Por Debbie Burke, Consultora Centro de Connecticut de Apoyo a los Padres ("CPAC")

a Ley federal del título, que llamamos "IDEA" por sus siglas en inglés (Individuals with Dissabilities Education Act) o "IDEA '97" porque fue aprobada en 1997, se considera piedra angular en lo que concierne a servicios pedagógicos para niños de cero a 21 años de edad con alguna incapacidad. Como madre que trabaja con otros padres de niños minusválidos, sé cuan importante es tener una comprensión de la Ley y pensé que sería útil referirme a su propósito, a su espíritu. Comenzando a escribir me encontré enredada en la terminología 'políticamente correcta' tan en boga, usando frases como ambiente menos restrictivo, igual oportunidad de participación y mayor participación de los padres. Me di cuenta entonces de que estaba concentrándome en la letra de la ley, no necesaria-

Los mandatos legales de la 'IDEA' son cruciales. Parece difícil imaginar una época en que tales protecciones no existían, pero hace apenas poco más de 25 años las escuelas públicas excluían a muchos niños minusválidos porque les era permitido hacerlo, y los no excluidos eran típicamente segregados en escuelas especiales o en aulas separadas. Fue entonces que los padres se unieron para provocar un cambio en la norma pública, señalando que la constitución de Estados Unidos especifica 'igualdad' y no 'separación'. En 1975 el Gobierno federal aprobó la Ley 94-142 Educación de todos los niños con incapacidades (Education of All Handi-

mente en su espíritu.

capped Children Act), la primera en exigir que todos los Estados proporcionen una "educación pública gratuita y apropiada" a los niños con incapacidades. La ley original ha sido refinada, enmendada y rebautizada, y hoy se la conoce por la "IDEA '97." Es la que sus-

tenta el Sistema para Infantes a Tres Años de Connecticut y sus servicios de Educación Especial Preescolar. La 'IDEA' beneficia a más de seis millones de niños (edades 0-21) en todo el país. La 'IDEA' es el fundamento de todos los servicios pedagógicos para niños con incapacidades, desde los recién nacidos hasta los de cinco y más años.

Cuando se construye algo, no importa lo que sea, la cimentación, el fundamento, es sólo el comienzo. La 'IDEA' es muy importante pero no es todo. Lo que da vida y sustancia a los programas de servicio a los niños con incapacidades y sus familias es la convicción simple pero poderosa de que todos los niños, tengan o no incapacidades, son iguales, que todos los niños y sus familias "valen la pena." Si la ley ha de significar algo, debemos valorar a todos los niños como tales. Padres y profesionales tenemos todos que partir de la premisa de que todos los niños pueden y han de poder adquirir aptitudes académicas y sociales, y que esa adquisición debe ocurrir satisfaciendo sus necesidades especiales, de modo que puedan desarrollarse y lograr el mayor grado posible de independencia. Debemos trabajar juntos para alcanzar ese objetivo. La "IDEA" es una ley

buena y poderosa, pero lo que conforma su verdadero espíritu es la manera de poner nuestras creencias en acción. Ese espíritu puede algunas veces ser eclipsado por puntos procesales de la Ley y sus reglas y reglamentos, pero es lo que acoplado a los mandatos legales puede lograr y logra un efecto positivo en las vida de nuestros niños y en el futuro no sólo de la educación pública sino de la sociedad en general.

El Centro de Connecticut de Apoyo a los Padres ('CPAC' por las siglas de Connecticut Parent Advocacy Center)) es una organización sin fines de lucro que cubre todo el Estado ofreciendo información y apoyo a los padres de niños con incapacidades y a los profesionales que trabajan con ellos. El equipo humano del Centro está integrado por padres de niños minusválidos que ayudan a otros padres a aprender cómo participar con más eficacia en la educación de sus hijos. Usted puede comunicarse con el CPAC llamando al (800) 445-2722 o al (860) 739-3089.

ave-the-Date! The 17th Annual Division for Early Childhood (DEC) Conference – Early Childhood in the New Millennium: Recommended Practices for the

Future – will be held December 2-5, 2001 at the Boston Marriott Copley Place. DEC is an international organization for professionals and parents interested in and/or working with young children with disabilities and their families. This conference provides an opportunity to learn about national trends in policy and recommended practices associated with young children including those with special needs.



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www.ideapractices.org

Lots of articles, calendar of upcoming conferences

www.state.ct.us/sde/

The Connecticut State Department of Education; includes calendar of events, lots of easily accessible education information

www.birth23.org

The Connecticut Birth to Three System; includes fact sheets, many in both English and Spanish

www.nichcy.org

Information on special education and related services; English and Spanish

www.ed.gov/offices/OSERS/IDEA/

The latest amendments made to the Individuals with Disabilities Act in 1997

www.ed.gov

U.S. Department of Education; lots of education-related material and curriculums

www.ed.gov/databases/ERIC_Digests/ed433668.html
An overview of the Individuals with Disabilities Education
Act Amendments of 1997 and other related information

www.ideadata.org/

Reported data collected by the U.S. Department of Education; tables and statistics available

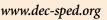
www.lrp.com/ed/freelib.htm Federal Education Statutes and Regulations

www.lrp.com

LRP is an organization that disseminates information on the legal aspects of the IDEA

www.edlaw.net/

Information on the ADA, transporting students with disabilities and more



The Division of Early Childhood is an international organization for professionals and parents interested in and/or working with young children with disabilities and their families.

www.nectas.unc.edu

National Early Childhood Technical Assistance System – provides information about the law

www.cpacinc.org

Connecticut Parent Advocacy Center provides information on parent advocacy

http://specialed.about.com/education/specialed/msub23.htm
Information on IDEA regulations and Special Education law



A Comparison of the Connecticut Birth to Three System and Preschool Special Education

ome children and their families are introduced to a school district after having received services through the State's Birth to Three System. For others, a child and family's first contact

with the school can come after concerns about a child's development have been identified. The following side-byside comparison is intended to assist families and others in understanding the similarities, as well as some of the differences, between the state's Birth to Three System and special education.

| | Birth to Three | Special Education |
|---------------------------|--|---|
| Governing Federal Laws | Part C of the Individuals with Disabilities Education Act (IDEA). | Part B of the Individuals with Disabilities Education Act (IDEA). |
| Ages Served | Children with disabilities and significant developmental delays, ages birth through 2. | Children with disabilities, ages 3 through 21 or upon graduation from high school. |
| Goal of the Program | The focus is on helping the family meet the developmental needs of their child with a delay or disability. | The focus is on the child with a delay or disability and his/her educational needs. |
| Evaluation | Two or more professionals from different disciplines complete a developmental evaluation of all 5 areas of development. | A team of professionals completes an evaluation in the area(s) of suspected disability. |
| Eligibility | A child must have a diagnosed physical or mental condition that has a high probability of resulting in a developmental delay; or the child demonstrates a delay of 2 standard deviations below average in one area of development or a 1.5 standard deviation below average in 2 or more areas of development. | To be eligible, a child must fall within one of the special education disability categories that include: mental retardation, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments or specific learning disabilities, developmental delay and because of the disability needs special education. |
| Family Involvement | Families must be involved in the process to develop and implement the IFSP. | Parents must be members of any group (e.g., planning and placement team) that makes decisions on the education of their child. |
| Service Coordination | Each eligible infant or toddler is assigned a service coordinator to work together with the family on the process of evaluation, IFSP development and implementation, and coordination of services, including access to other state and community resources. | Under special education law, there is no requirement that a service coordinator be assigned to a child and their family. |
| Type of Plan | An Individualized Family Service Plan (IFSP) is used to document the desired outcomes for the family and the child, as well as the services to be provided. IFSP's are reviewed at least every six months with the service coordinator and rewritten | An Individualized Education Program (IEP) is used to document the child's educational goals, objectives, services and program, and measure progress. IEP's are reviewed periodically but not less than annually. |
| Services | All services are termed "early intervention services" which are developmental services provided to support the family's ability to meet their child's developmental needs and the family's desired outcomes. | Special education is an educational service or program that is instructional in nature. Related services (such as OT, PT and Speech) are provided when they are required in order to assist a child in obtaining benefit from the special education program. |
| | Services are provided by any of the state's approved Birth to Three programs. | Services are provided by local and regional school districts. |

| | Birth to Three | Special Education |
|---------------------------|--|--|
| Service Delivery Model | Enrollment in the Birth to Three System is voluntary. | School districts are required to provide special education to children, ages 3 through 21. |
| | The type(s), frequency, location and duration of services, including personnel providing services, are determined through the IFSP process. | Services are determined by a planning and placement team and documented on an IEP. |
| Location of Services | Natural Environments Early intervention services are to be provided in <i>natural environments</i> (such as the child's home or in other sites in the community where infants and toddlers without disabilities participate) in order to take advantage of natural learning opportunities and the child and family's normal routines of the day. | Least Restrictive Environments In special education, children with disabilities are to be educated with children who are not disabled. Special classes, schooling or other removal of the child from the regular education environment occurs only when the nature and severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily. |
| Transition | The child's service coordinator will convene a transition conference for all children at least 90 days before their third birthday. | A representative of the responsible school district will participate in the transition conference convened by the Birth to Three System. |
| | The transition conferences will be convened with representatives of the child's school district and/or with providers of other appropriate services or programs. | By the child's third birthday, an individualized educational program (IEP) has been developed and is being implemented for the child, if the child has been determined eligible for special education. |

Program Updates

BIRTH TO THREE

By Linda Goodman, (860) 418-6147

n the Winter 2000 newsletter, I mentioned that we had requested proposals from organizations that wished to help create a Family Leadership Initiative for the Birth to Three System. I am pleased to announce that PATH - Parents **Available to Help** – was awarded a contract to do that for us. They have hired 5 part-time parent coordinators, one in each region of the state. These coordinators will network with Birth to Three families and identify parents who are interested in getting more involved with the System. That might be serving on a local or state Interagency Coordinating Council, participating in monitoring programs, serving on committees or task forces, reviewing materials, helping to review proposals, or a myriad of other activities. If you are interested please contact Karen Cubellotti at PATH: (800) 399-7284. She will put you in touch with a regional coordinator.

Training and coaching will be provided.

We have 3 new Birth to Three programs this year: one in the Stamford area, ARI of Connecticut; one in the Norwalk area, Easter Seal of Southwestern Connecticut; and one in the Norwich/New London area, Easter Seal of Southeast Connecticut. We hope that these additional programs will make services more accessible to families.

In April, a group of about 25 (Birth to

Three staff, providers, par-

ents and others) met to look at all of the competing priorities for change that we have, including:

- the recent Self-Assessment,
- the 2001 Outcome Study,
- provider priorities and
- departmental initiatives.

Out of that information will come the next strategic plan for the Birth to Three System. It will detail what we hope to accomplish over the next

three years. As soon as it is completed, it will be posted on our web site.

I hope that you'll take a look at our newly redesigned web site (www.birth23.org). Our goal is to make it faster to navigate and easier for families to find the information they want. Please send an email from the site telling us how you like it and giving any suggestions because we're always looking for ways to improve it.

PRESCHOOL SPECIAL EDUCATION

By Maria Synodi, (860) 807-2054

There are federal and state laws that affect young children with disabilities and their families. The Individuals with Disabilities
Education Act (IDEA) is the law that most professionals and families become familiar with first. IDEA is the law that provides Birth to Three services to an infant or toddler with a disability and to their family. IDEA is the law that provides a preschool-age child, who has a disability, with a pre-academic and developmental opportunity through special education.

Most of us have come to know and depend on the basic principles of the

IDEA. The law is used to develop, implement and evaluate the best practices for children and their families. However, just 25 years ago, there was no law called IDEA. Judy Heumann, former Assistant Secretary for the Department of Education's Office of Special Education and Rehabilitative Services, herself a person with a disability, often reminds people that the first time that she entered a school building, she was 10 years old. Twentyfive years ago many schools did not accept children with disabilities, and many children were educated at home or in institutions. Now, 25 years later, every state in the country provides early intervention services for children with disabilities, who are aged birth to 3, and provides special education for every eligible child from age 3 to 21.

IDEA has changed to keep pace with the needs of young children and their families. The basic principles for special education have changed as well. These principles now include high expectations for children, access to the general curriculum, parental involvement and services in regular classrooms so that every child will meet their developmental goals and, whenever possible, will reach the same level as all children.

IDEA will be reviewed and revised over the years with a goal towards the continued improvement of the law. IDEA's 25-year anniversary is a reminder that laws are made with good intentions and this law's intent was to provide access and equal educational opportunity for children with disabilities. That's a good thing.



PARENT CONNECTIONS

By Karen Biernat, President, Connecticut Chapter of the Alexander Graham Bell Association for the Deaf and Hard of Hearing and member, the Interagency Coordinating Council (ICC)

you just learned your child has a disability and the news is devastating. When my daughter was diagnosed with a severe-to-profound, permanent hearing loss after surviving bacterial meningitis, I was confronted with so many emotions. Initially I was relieved that she had survived a life-threatening illness at the age of 10 months. Then I was faced with her permanent disability and the grieving that often follows. After the diagnosis of permanent hearing loss, I was sent on my way with no materials to read, no names of other parents to contact and no immediate referral to the Birth to Three program. Fortunately, with one phone call, I was

quickly hooked up to the Birth to Three program. The enrollment process was fast and efficient, but there was still something lacking. I needed to meet other parents of children with permanent hearing loss, to see that they had survived the grieving process, and that the parents and their children were OK. I began reading books, doing research on the internet and making phone calls. Most of the books I read recommended finding a parent support group.



At the time of my daughter's diagnosis, I was unable to find a parent support group. We had a wonderful early interventionist working with our family, but I still felt a strong need to connect with other parents. Dr. David Luterman and Ellen Kurtzer-White of Emerson College conducted research into what parents' needs were when first learning of their child's hearing loss. They discovered that those parents' *predominant* need was contact with parents of other hearing impaired children.

I assume that parents of children with other disabilities have this same need. I was eventually able to find other parents through the internet, the AG Bell Association and our Birth to Three provider. If you haven't connected with other parents yet, I urge you to do so. By meeting other parents, I have learned so much. Parents are often willing and able to share more than you could ever learn by reading a book. While the Birth to Three program gave me the tools to become my daughter's first and most important teacher, fellow parents have given me the emotional strength to do this task. They have taught me to enjoy my child for who she is, to talk about my fears and to help me cope with a diagnosis that will affect the rest of our lives.

PARENT EMPOWERMENT

By Angela Russell, Parent Leader

Perhaps the most valuable asset anyone can give to a parent or community today is empowerment. All too often an assumption is made that parents do not know what is best for them, their families and their communities. But parents who are informed consumers can advocate for themselves, their families and their communities!

Although there are several challenges for building parent leadership, one must embrace the belief that the law is there to help children and their families. We, as parents, have the ability to integrate both personal and professional skills so that we can fully respond to the needs, concerns and interests that parents and families share.

One of the primary benefits of the law is access to resources, including community services and networking with others who share similar concerns. Most often, parents need only know the direction and will work hard to accelerate and move forward toward change.

We all have hopes and dreams. Parental empowerment is difficult to measure but tremendously valuable in helping us reach our dreams!



Preschool Special Education:

THE SPIRIT OF THE LAW

By Jane Bisantz of Jane Bisantz and Associates, LLC

he years between birth and 3 are magical. Magic is hard to legislate, but the federal Birth to Three law (Public Law 105-17) provides guidance on how to let the magic happen. It does this by recognizing that early intervention providers are not the magicians; families are.

The law mandates that our services be



provided in *natural environments* – homes and community settings. Birth to Three providers don't arrive at our treatment centers in the morning and stay there all day. We pack up our bags and travel. We feel the weather and experience the road conditions. These are things that we have traditionally expected families to do.

The law says that Birth to Three services must be family focused, not provider focused or even child focused. This means that providers don't run the show - families do. Providers are mandated to ask each family about their priorities, needs and concerns, and to base every Individualized Family Service Plan (IFSP) on this information. The law requires that that we, as providers, open our minds and hearts to cultures, ideas, ideals and goals that are not our own. We need to be learners as well as teachers. Again, we have traditionally expected families to do these things!

The law tells Birth to Three providers that we must be *transdisciplinary* in our service delivery. We need to drop our professional boundaries, and actively collaborate and share responsibilities with the other members of each early intervention team. The law urges us to spread our knowledge across disciplines, and to learn new things from our colleagues and from the families we serve while we mentor them.

I used to think of laws as obstacles to the accomplishment of truly important things. But the Birth to Three law actually focuses us on what is important – families and their dreams and aspirations. The values the law embodies – tolerance, flexibility, open heartedness, willingness to learn and willingness to share what we know – are more than just the basis of effective early intervention. Many of us recognize them as the foundation of a vital and rewarding life.

BIRTH through NEWS

Information for Families and Professionals

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An Open Invitation From the Interagency Coordinating Council

The Birth to Three Interagency Coordinating Council (ICC) is comprised of parents of children with a developmental delay or disability, early intervention providers, members of the medical community, the legislature, the childcare community and agency representatives who work together on behalf of infants, toddlers and their families.

The ICC would like to extend an open invitation to you, or someone you know, to attend an ICC meeting. An open public comment period is scheduled at each meeting. Share your opinions, thoughts or feelings regarding what is working or what needs improvement in the Birth to Three System. The ICC is interested in

hearing directly from people involved in the System.

The ICC usually meets on the second Monday of every other month from approximately 9:00 a.m. until 1:00 p.m. Most meetings are held at Infoline, 4th floor, 1344 Silas Dean Highway, Rocky Hill, CT. Future dates include June 11, August 13, October 15 and December 10.

If you are unable to attend a meeting but have information to share, please contact Eileen McMurrer by phone at (860) 418-6134 or by fax at (860) 418-6003. Additional information about the ICC, including directions to meetings, can be found at the newly redesigned Birth to Three web site at www.birth23.org

ental Health services are available for HIV-affected children and youth in Hartford, New Haven, Fairfield and New London counties. Services vary across agencies but may include individual, family or group sessions. For more information call:

- The Village for Children and Families, Hartford (860) 527-4224
- Clifford W. Beers Child Guidance Clinic, New Haven (203) 772-1270
- Child Guidance Center of Greater Bridgeport
 (203) 376-5361 – Bridgeport
 (203) 255-2631 – Fairfield
- Community Child Guidance Clinic, Manchester (860) 643-2101
- Meriden Child Guidance Clinic, Meriden (203) 235-2815
- Child Guidance Center of Southern CT, Stamford (203)324-6127
- Child Guidance Clinic of Southeastern CT, Inc, New London (860) 437-4550



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