

A HISTORY OF SERVING ILLINOIS CHILDREN WITH SPECIAL HEALTH CARE NEEDS



SINCE 1937



1900 - 1935

The Beginning

Illinois Initiatives

Clinics were conducted by the **State Dept. of Public Health** during the 1916-1917 poliomyelitis epidemic.

The **Illinois Association for the Crippled** was organized and continued clinics begun by the **IL Dept. of Public Health**.

A **Dept. of Public Welfare** census identified 10,111 crippled children in Illinois.

1916-
1917

1921

1930

National Initiatives

1912

The **Federal Children's Health Bureau** was established in the Dept. of Commerce and Labor.

1913

The **Children's Health Bureau** was transferred from the Dept. of Commerce and Labor to the Dept. of Labor.

1921

The **Sheppard Towner Act** provided Grants-in-Aid to states to develop health services for mothers and children. This bill lapsed in 1929.

1935

Enactment of the **Social Security Act, in Title V, Section 504**, enabled states to "extend and improve services for crippled children and for medical, surgical, corrective, and other services and care for and facilities for diagnosis, hospitalizations and aftercare for children who are crippled or who are suffering from conditions leading to crippling."

"A crippled child, for the purpose of administering funds obtained from the Federal government under provisions of the **Social Security Act**, was considered anyone up to the 21st birthday afflicted with a congenital or acquired deformity, disorder of locomotion or disease of the extremities or skeleton which is likely to yield to medical and surgical care."

1936 - 1939

The Beginning

Illinois Initiatives

An Executive Order of the Governor of Illinois created the **Division of Physically Handicapped Children in the Department of Public Welfare** to administer crippled children's services and to receive federal funds.

Paul Harmon, MD was the first director of the Division.

The **Surgical Institute for Children** (predecessor of the Dept. of Orthopedics, University of Illinois Research and Educational Hospital) was administered by the **IL Dept. of Public Welfare**. State funds appropriated to the Institute were accepted as state matching funds for Title V.

The first **Division Clinic** was held in Shelbyville, IL June 25. Approx. 75 children attended and 17 cases selected for care. In FY 1936-37, 60 clinics were held at 30 different sites.

An **epidemic prevalence of infantile paralysis** in Chicago and downstate occurred in the summer of 1936 and 1937.

A **social worker** was added to the staff. Prior to that time the Division employed nurses.

A **two year survey** identified approximately 26,000 children with crippling deformities in Illinois. (This was a W.P.A. project.)

The Division's name was changed to **Division for Physically Handicapped Children**.

Eight Division field offices were located in Rockford, Champaign, Peoria, Springfield, Vandalia, Mt. Vernon, E. St. Louis, Chicago.

196 Clinics were held.

8,172 children examined.

National Initiatives

In FY ending June 30, 1936, Congress appropriated a total of \$2,850,000 to be used for Grants-in-Aid to states to establish services for "crippled children" through Title V of the Social Security Act. The emphasis on services was to rural and economically distressed areas.

1936

1937

1939-
1940

1940 - 1946

Expanding Services

Illinois Initiatives

Administrative responsibility for the Surgical Institute for Children and other hospital facilities was transferred from the Dept. of Public Welfare to the University of Illinois. The **Division of Physically Handicapped Children** was also transferred to the University. **Lawrence Linck** became the Director of the Division. (He was the only Director who was not a physician.)

The Division name was changed to the **University of Illinois Division of Services for Crippled Children (DSCC)** to conform with the Federal designation of funds for "Crippled Children Services."

The HB 463 of the 64th General Assembly passed the **first state appropriation** for DSCC.

In 1943, a **speech & hearing consultant** was added to the DSCC staff.

In 1943, a special **cerebral palsy clinic** was held. Care began for children with rheumatic fever, congenital and acquired **heart disease** at a clinic staffed by a certified cardiac pediatrician. Clinics were established for the treatment of epilepsy and **convulsive disorders**.

A **Division staff photographer** provided motion picture and still photography that was used as a part of medical records, especially for the Cleft Palate Clinic.

Herbert Kobes, MD became the Division Director in 1945.

National Initiatives

1940-1946

States began to expand care to include children with rheumatic fever and heart disease. \$3,870,000 annually was appropriated to states from 1940-1946.

1941

1942

1943-1945

1946

The Children's Bureau was transferred from the Dept. of Labor to the **Federal Security Agency**.

1946-1955

States broadened "crippled children's" programs to such conditions as cerebral palsy, eye disorders amenable to surgery, cleft palate, burns, hearing impairment, epilepsy, etc. Appropriations ranged from \$7,500,000 in 1947 to \$10,843,400 in 1955.

1947 - 1959

Expanding Services

Illinois Initiatives

1947

A press release marking DSCC's tenth anniversary, reported more than 50,000 children had been registered since 1937. 12,000+ children had received 33,000 specialized clinic exams. The release noted that the title, Division of Services for Crippled Children "has become a symbol of opportunity for many thousands of children."

1953

SB 547 allowed the Division to extend its services to municipalities over 500,000 in an exploratory program. No additional funds were made available.

1956

The Center for Handicapped Children became part of DSCC to serve children with complex multiple handicaps through comprehensive, coordinated and multidisciplinary diagnostic and treatment services.

1957

The IL General Assembly formally established DSCC's administration by the University of Illinois; Chapter 144, Section 67.1. Vol. 3 of the Illinois Revised Statutes, 1964. From that time, DSCC appropriations were incorporated into University appropriations.

1958

District offices were located in Chicago, Rockford, Rock Island, Peoria, Normal, Urbana, Springfield, Olney, Harrisburg, Belleville, Carlinville, and Mount Vernon. Staff included a nursing consultant and a secretary. Larger offices had a medical social consultant and/or speech and hearing consultant. District Offices served from 3-10 counties.

1959

Edward Lis, MD became the Division Director.

National Initiatives

1949

United Cerebral Palsy and affiliates across the nation were founded by Leonard and Isabelle Goldenson.

1952

National Association of Retarded Children was formed as a result of the Mid-century White House Conference on Children and Youth.

1953

The Federal Security Agency became known as the Department of Health, Education and Welfare (HEW).

1955

Polio vaccine became available.

1956

Appropriations for the Crippled Children Program reached \$15,000,000.

1960 - 1969

Expanding Services

Illinois Initiatives

1962

DSCC celebrated its 25th anniversary. 19,598 children were registered. DSCC maintained 12 offices (regional and district).

1964

A report listed 204 general clinics, 59 specialty clinics organized in 38 communities throughout the state. DSCC had 7 regional offices, 5 district offices and a central administrative office. Children served included those with orthopedic conditions, rheumatic fever and rheumatic heart disease and deformities of the heart, conditions of the nervous system such as cerebral palsy, epilepsy and paralysis following accidents or disease, congenital and acquired defects which respond to plastic surgery, speech defects associated with organic conditions, hearing loss and deafness. 18,908 children were registered.

1969

DSCC reported to the Federal Dept. of Health, Education and Welfare, the charges for a **cardiac surgery was \$300 and \$500 for open heart surgery.**

At a Macomb or Decatur Clinic on May 22, an unknown child was the 250,000th child examined at a DSCC general clinic. More than 5,000 clinics had been held in 69 cities with an average attendance of 50 children.

National Initiatives

1962

National Institute of Child Health and Human Development - Established for the purpose of conducting and supporting research and training related to maternal and child health and human development.

1963

The measles vaccine was licensed.

1964-1965

HeadStart was enacted.

1965

Medicaid (Title XIX) established to provide health insurance coverage to low income women and children including the aged, blind and disabled.

1967

Congress mandated State Crippled Children's Programs to provide service to children regardless of geographical region by 1975.

1969

Title V transferred to the U.S. Public Health Service.
Early Periodic Screening and Diagnosis and Treatment (EPSDT) was required for Medicaid-eligible children effective July 1.

1970 - 1979

Expanding Services

Illinois Initiatives

National Initiatives

1972

Congress mandated that Head Start must serve handicapped children. Although the Medicaid statute was amended in 1967 to include EPSDT, it was not until 1972 that the regulations for EPSDT were published.

1973

Congress enacted the Section 504 of the **Rehabilitation Act of 1973**. Health Maintenance Organization Act- The law applied minimum, uniform standards in all 50 states for a health insurance organization to qualify as an HMO.
Children's Defense Fund- Founded by Marian Wright Edelman, the Children's Defense Fund is a non-profit, private organization that advocates for all children who cannot vote, lobby, or speak for themselves.

1975

The **Education of All Handicapped Children Act** was enacted by Congress.

1976

Congress established a separate categorical program to assist **disabled children receiving SSI**. SSI referred blind and disabled children under 16, receiving SSI benefits to State Crippled Children's programs for rehabilitation services.

1978

In 1978, Gov. James Thompson designated DSCC as the state agency to administer the **SSI-Disabled Children's Program**.

The PL 94-142 Compliance Bill (Education of All Handicapped Children Act) amended the School Code and was passed by the 80th General Assembly.

1979-1980

71 interagency **O/A clinics** were held in the Chicago area.
DSCC and the IDPA collaborated to discharge **ventilator-dependent child** to home.

1980 - 1985

Bringing the Tradition of Excellence into a New Millennium

Illinois Initiatives

The **DSCC Advisory Board** was reactivated after a period of inactivity.

1980

As part of the Children's Home Health Network of Illinois, DSCC received a **3 yr. Grant** from HHS, Division of Maternal and Child Health to develop a Home Care model for **ventilator-dependent** children. DSCC managed 11 children receiving Home Care services at the end of 1983.

1983

National Initiatives

Title V was converted to a **Block Grant** as part of the **Omnibus Budget Reconciliation Act (OBRA '81)**. The Lead-Based Poisonion Prevention Program, SIDS Program were consolidated under the MCH Program. The Supplemental SSI Program for Blind and Disabled Children, Genetic Diseases Program and the Hemophilia Diagnostic and Treatment Centers Program were consolidated under the CCS Program. OBRA '81 also permitted states to develop **Home and Community-based Waiver Programs**.

1981

Emergency Medical Services for Children Act enacted as part of Title V.

Baby Doe Rules - These rules, issued by the Department of Health and Human Services, were developed to ensure that the withholding of life-sustaining treatment for newborns with handicapped conditions would no longer occur.

1984

The term "Crippled Children" was changed to "Children with Special Health Care Needs" in the consolidated Omnibus Budget Reconciliation Act of 1985.

1985

1986 - 1989

Bringing the Tradition of Excellence into a New Millennium

Illinois Initiatives

73 children were receiving care through the **Home Care Program**. An **interagency agreement** was signed between the **Dept. of Public Aid** and the **Board of Trustees of the University of Illinois** for the Division regarding the administration and case management of the **Title XIX Model Waiver** for severely disabled children.

February 10, DSCC adopted the first agency Administrative Rules. Eligible medical impairment categories included: orthopedic impairments, nervous system impairments, cardiovascular impairments, external body impairments, hearing impairments, speech impairments, cystic fibrosis, hemophilia and inborn errors of metabolism.

Administrative Rules **amendments added a new category: eye impairments**.

Dr. Edward Lis, M.D., was named Pediatrician of the Year by the Illinois Chapter of the American Academy of Pediatrics.

National Initiatives

Amendments to the **Education of Handicapped Amendments of 1986** gave states funds to plan and develop a system of comprehensive services for children **zero to three** years of age. Funds to supplement services for children 3-5 were also provided.

Surgeon General C. Everett "Chick" Koop coined the phrase Children with Special Health Care Needs to replace the old Crippled Children Services (CCS).

Pediatric AIDS projects funded through Title V.

Pediatric AIDS projects funded through Title V.

The Omnibus Budget Reconciliation Act of 1989 redefined state CSHCN program mission. Programs were to "provide and to promote family-centered community-based, coordinated care for CSHCN." The act also defined care coordination and designated at least 30% the Grant Fund for CSHCN.

OBRA Amendments to Title V: reintroduced accountability; needs assessments required; annual reporting requirements; explicit focus on family-centered, community-based, coordinated care.

1986

1986

1987

1988

1989

1989

1990 - 1995

Bringing the Tradition of Excellence into a New Millennium

Illinois Initiatives

Administrative Rules amendments added a new category: **urinary system impairments**.

Robert Biehl, M.D. became the Division Director.

Dr. Miriam Kalichman became the medical director for the Center for Handicapped Children following the retirement of Dr. Edward Lis, M.D.

Dr. Robert Biehl, M.D. was named Pediatrician of the Year by the Illinois Chapter of the American Academy of Pediatrics.

The Division of Services for Crippled Children changed its name to The Division of Specialized Care for Children to reflect the Division's work and to update terms.

The **Children's Health Information Management System (CHIMS)** was developed and implemented statewide. This system automated enrollment and claims management.

DSCC was chosen by ISBE to develop and implement a **Central Billing Office for EI**. After statewide implementation, the CBO was transferred to IPHCA on July 1, 1999.

1990

1991

1994-
1995

1995

National Initiatives

Maternal and Child Health Bureau (MCHB) was established to administer Title V.

The **Americans with Disabilities Act** was enacted by Congress.

FDA approved a cochlear implant device for children 2 years and older. Bright Futures - Initiated in 1990 and guided by MCHB, Bright Futures developed comprehensive health supervision guidelines with the collaboration of four interdisciplinary panels of experts in infant, child, and adolescent health.

States were required to submit annual grant applications and annual reports in a **standard reporting form**.

Family Voices, a grass roots network of families and friends of children with special health care needs is formed.

The Government of Performance Results Act (GPRA) required MCHB to begin to develop plans to report performance.

1992

1993

1996 - 2000

Bringing the Tradition of Excellence into a New Millennium

Illinois Initiatives

National Initiatives

DSCC began supporting certain cochlear implant devices.

1996

1996

The Health Insurance Portability and Accountability Act (HIPAA) was enacted to protect health insurance when a person changes or loses their job, and required standards for electronic health care transactions.

TANF (Temporary Aid for Needy Families), the Welfare Reform Legislation enacted (termination of AFDC). Limits lifetime benefits; forces return to work; including requirements to reduce teen pregnancy.

Charles N. Onufer, M.D. became Division Director.
DSCC completed the first DSCC Family Survey of DSCC and SSI families.

1997

1997

The **Balanced Budget Act of 1997** expanded health care coverage for children by establishing the **State Children's Health Insurance Program (SCHIP)**.

In July, DSCC submitted its Application and Annual Report to MCHB, reporting on 5 required **Performance Measures for CSHCN and 2 State Performance Measures**.

Development started on a **DSCC Internet and Intranet Site**. Intranet access was implemented statewide in 1999.

1998

1998

The **Title V Information System** (at www.mchdata.net) was established by MCHB. CSHCN program began to use the Electronic Reporting Package (ERP) to report to the Bureau. Required Performance Measures included SSI recipient services, direct services, medical home for CSHCN, insurance for CSHCN and family participation in the CSHCN program.

The **Hearing Screening for Newborns Act** mandated all birthing hospitals to conduct universal newborn hearing screening by December 31, 2002.

The **Center for Handicapped Children** changed its name to the **Children's Habilitation Center**.

The **Family Advisory Council** was developed and held its first meeting.

A **Family Liaison Specialist** was hired.

1999

2000 - 2004

Services for CSHCN and Their Families

Illinois Initiatives

DSCC publishes the first family newsletter, Special Addition, in both English and Spanish versions.

In March 2001, "Friends of DSCC" was established as a gift fund to support certain needs of families that are not normally eligible through the Core Program.

DSCC initiates a state plan for integrating the medical home concept.

DSCC expanded the Medical Advisory Board to 15 members to include the Chair of the Family Advisory Council.

The conference room at the Chicago Administrative office is named the Edward F. Lis, M.D. Conference Room.

2001

National Initiatives

Healthy People 2010, a 10 year Action Plan for CSHCN begins. The Action Plan identifies 6 core outcomes for CSHCN.

National Survey on CSHCN begins October 2000-July 2001

Bright Futures Guide for families developed by Family Voices.

2000

Illinois newborns began to be screened for 28 metabolic conditions using Tandem Mass Spectrometry. DSCC supported follow-up diagnostic evaluation when no other financial support was available.

Dr. Charles N. Onufer, M.D. was named Pediatrician of the Year by the Illinois Chapter of the American Academy of Pediatrics.

Governor George Ryan proclaims 2002 Year of the Medical Home.

2002

2002

Health Insurance Portability and Accountability Act (HIPAA). Regulations designed to: drive down cost of health care by using universal diagnostic and billing codes to aid in continuity of care and protect the security and privacy of patient data.

In July, DSCC began administrative claiming for children enrolled in Medicaid and DSCC.

DSCC's percentage of MCH Block Grant was reduced from 32.1% to 30%.

2003

2003

The privacy/security rules for personal health information under the Health Insurance Portability and Accountability Act (HIPAA) were effective on April 14th.

Illinois Initiatives

The first annual statewide Transition Conference: *Today's Student, Tomorrow's Adult* was held June 7-8 in Springfield to offer YSCHN, educators, families and community representatives planning for positive post school outcomes.

DSCC completed its second Family Survey of families served by DSCC and newly referred SSI recipients to assist with the 5-year needs assessment for the MCH Block Grant.

The Memisovski Medicaid Suit improved access to healthcare for Kid Care children in Illinois.

DSCC partnered with other agencies with six grant activities promoting the Medical Home Model:

- ICAAP MCHB Grant for implementing a Medical Home quality improvement process in six demonstration practices for the first two years and an additional ten practices for the second two-year period.
- Illinois Head Start Association CATCH Planning Grant for improving access to a Medical Home for the 11% of children in Head Start without a primary care physician.
- NICHQ Learning Collaborative II for facilitating a quality improvement process in two practices.
- Chicago Epilepsy Foundation Grant for improving access to a Medical Home for children with epilepsy.
- An American Legion Grant to develop the Illinois Medical Home Care Coordination Organizer.
- Region 4 HRSA Genetic Collaborative Grant to develop a "Medical Homes in Action" website related to newborn metabolic screening. This website will provide information for both families and physicians about inheritable disorders.

2005

National Initiatives

2006 - 2008

Services for CSHCN and Their Families

Illinois Initiatives

All Kids became effective in July to provide health benefits for all IL children.

The Illinois Department of Healthcare and Family Services (HFS) implements a Primary Care Case Management program to assure All Kids/Medicaid recipients have a primary care physician (PCP)/medical home.

DSCC celebrated its 70th year having served over 1,000,000 Illinois CSHCN and their families.

DSCC continued involvement in the IL Medical Home Grant, working with 10 pediatric practices on developing a medical home for CSHCN.

DSCC collaborated with the AAP on the development of an online Care Notebook for families to use in managing their child's health information.

IL implemented screening of newborns for Cystic Fibrosis.

DSCC received HRSA funding for the 3-year Universal Newborn Hearing Screening and Intervention grant - Reducing Loss to Follow-up after Failure to Pass Newborn Hearing Screening. This state level quality improvement collaborative involves Rockford Memorial Hospital, Edwards Hospital, Adventist Health System and University of Chicago Hospital.

DSCC collaborated with the IL Chapter AAP, the Illinois School Nurses Association and the IL Dept. of Public Health on promoting public awareness of the Medical Home through a statewide coloring contest for students in grades 1-6.

DSCC revised and published the Medical Home Primer for Pediatricians and Family Physicians to help educate providers about Medical Home implementation.

National Initiatives

The National Survey on CSHCN to be repeated.

The National Children with Special Health Care Needs (CSHCN) survey is completed. The survey is sponsored by the Maternal and Child Health Bureau (MCHB) of the U.S. Department of Health and Human Services and conducted by the National Center for Health Statistics (NCHS) of the Centers for Disease Control and Prevention.

2006

2006

2007

2008

2008 - 2009

Services for CSHCN and Their Families

Illinois Initiatives

2008

DSCC collaborated with The Autism Program IMPACC grant: Improving Access to Community Care for Individuals with ASD and DD. This 3 year initiative included efforts to expand access to a medical home within IL primary care practices.

2009

Newborn Hearing Screening & Intervention grant quality improvement activities involved Carle Hospital, St. John's Hospital/Southern Illinois University and Bromenn Hospital/Illinois State University. A state team also participated with the NICHQ Improving Systems of Care for CYSCHN with Epilepsy & Newborn Hearing Program Learning Collaborative.

DSCC partnered with the IL Chapter AAP to implement the Building Community based Medical Homes for Children grant, funded by the Michael Reese Health Trust and the Chicago Community Trust.

The June 2009 issue of Managed Care magazine published an article evaluating the tools used to assess the medical home, including the Medical Home Family Survey, developed by DSCC.

DSCC partnered with the IL Chapter, AAP on the New Freedom Initiative State Implementation Grant - Integrated Systems of Services for IL CYSCHN and their families. This 3 year initiative will improve access to medical home and transition into adult services programs for youth with special health care needs.

Tom Jerkovitz is appointed the new Director of DSCC at the November U or I Board of Trustees meeting. Mr. Jerkovitz has a distinguished career in health care administration within the state of Illinois and in the private healthcare industry.

National Initiatives

2008

The Children's Health Insurance Program Reauthorization Act (CHIPRA or Public Law 111-3) reauthorized the Children's Health Insurance Program (CHIP) through FY 2013. This law preserves coverage for the millions of children who rely on CHIP and provides the resources for states to reach millions of additional uninsured children.

2009

The American Recovery and Reinvestment Act (ARRA) is signed into law on February 17, 2009. The Act specifies appropriations for a wide range of federal programs, and increases or extends certain benefits under Medicaid, unemployment compensation, and nutrition assistance programs. More information is available at www.recovery.gov.

2010

Services for CSHCN and Their Families

Illinois Initiatives

DSCC continued the third year of Universal Newborn Hearing Screening and Intervention grant - efforts focus on including additional hospitals in Northern Illinois.

2010

2010

National Initiatives

The Affordable Care Act is signed into law on March 23, 2010. The Act will not be implemented all at once although portions of the law have already taken effect. Other changes will be implemented through 2014 and beyond. More information is available at www.healthcare.gov.

Mission Statement:

DSCC's mission focuses on public service, education and research as a basis to provide, promote and coordinate family-centered, community-based, culturally competent care for eligible children with special health care needs in Illinois.

In 2007, DSCC enjoyed celebrating a 70 year tradition of serving over 1,000,000 families with CSHCN in Illinois.

