

Illinois

Division of Specialized Care for Children (DSCC)

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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.

I. DIRECT HEALTH CARE SERVICES

Direct health care services are defined as services generally delivered between a health professional and a patient in an office, clinic or emergency room. For example, well child care visit; visit to doctor for an acute health care condition (e.g. earache); follow-up visit to a specialist for a chronic condition (e.g. asthma, diabetes, sickle cell disease), physical therapy, occupational therapy, respiratory therapy, inpatient and outpatient medical services, allied health services, lab, etc.

ELIGIBILITY CRITERIA FOR DIRECT CARE SERVICES

Age:

Any Illinois child/young adult from birth to age 21 years of age.

Residency:

The child/young adult must live within the state of Illinois and be U.S. citizens or have parents who are lawfully admitted to the U.S. on a visa, which permits them to remain

permanently. Children/young adults whose families regularly return to the state to perform agricultural labor may also meet residency requirements. Also, children/young adults of members of the US military with assignment to Illinois may be eligible.

Medical:

Medically eligible children are those who have conditions that: are amenable to treatment; are expected to be long lasting or lifelong; have a life expectancy sufficient to realize the benefits from the treatment; have a need for long-term, highly specialized medical care, including related rehabilitative services; and involve multiple physical defects, and disabilities.

Eligible Conditions:

Eligible conditions may be congenital or acquired in origin and involve the following impairments:

- Cardiovascular impairments primarily affecting the heart and larger blood vessels
- Cystic fibrosis
- External body impairments, including the oral and nasal structures and severe oro-craniofacial deformities
- Eye impairments, excluding isolated refractive errors
- Hearing impairments (loss of hearing or deafness of at least 30 decibels in two frequencies, or a 35 decibel loss in one speech frequency involving one or both ears)
- Hemophilia and similar chronic defects of coagulation or chronic hemorrhage
- Inborn errors of metabolism (only congenital disorders)
- Nervous system impairments affecting the brain, spinal cord, or peripheral nerves
- Orthopedic impairments affecting bones, joints, or muscles
- Speech impairments arising from any structural defect of the organs responsible for vocalization or neurological defects specific to orderly speech development *
- Urinary tract impairments, including chronic organic impairments affecting the kidney, ureter, bladder, and/or urethra **

* Developmental language deficits are not eligible.

** Children requiring chronic renal dialysis and/or renal transplant are not eligible.

Excluded Conditions:

- Acute conditions, except those children with a resulting disability may be eligible after completion of medical treatment for the acute condition
- Children considered to be blind and not amenable to ophthalmologic intervention
- Malignancy*
- Persistent vegetative state
- Psychological dysfunction
- Renal impairments requiring chronic renal dialysis and/or renal transplant

*While malignancy is not an eligible condition, certain impairments resulting from a malignancy may be eligible.

Financial:

General Financial Eligibility:

Illinois families whose children are found to have eligible medical conditions may apply for financial assistance. Financial eligibility is determined by the family's size and total annual income. Financial eligibility is based on 285% of the Federal Poverty Guidelines (FPL) as published by the Department of Health and Human Services each year. Families with total income not more than 285% of the Federal Poverty Level, adjusted for family size, may be eligible for DSCC financial support. Families with incomes below 200% FPL with no insurance will be required to apply to Medicaid/KidCare.

Financial Eligibility for Initial Screening:

This program does not support “screening,” however, initial diagnostic services to determine the presence of an eligible medical condition are provided without regard to ability to pay. Families are expected to use any existing insurance or other 3rd party benefits including Medicaid/KidCare prior to seeking payment from DSCC for any needed diagnostic service.

Family Co-Payment or Financial Participation Requirements:

Not applicable.

DIRECT CARE SERVICES (PROVIDED OR PAID FOR):

DSCC provides or authorizes payment for a broad array of direct health care services related to the eligible condition including:

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| Adaptive Equipment | Limited convalescent and home-based care |
| Augmentative Communication Devices | Nutritional evaluation and guidance |
| Clinic visits | Physical and occupational therapy |
| Consultative services | Prostheses and Orthoses |
| Consumable Supplies | Services to treat severe oro-craniofacial deformities |
| Diagnostic evaluations | Specialized dental care |
| Doctor visits | Speech and hearing therapy |
| ER care | Specialized prescriptive drugs |
| Hearing Aids | Van lifts (one time purchase) |
| Hospitalizations | Walkers |
| Inpatient medical and/or surgical treatment | Wheelchairs |
| Lab and X-rays | |

Excluded Direct Care Services:

- Cosmetic surgery
- Experimental or investigative services/devices/drugs
- Mental health services
- Organ transplantation and related anti-rejection drugs
- Primary care services required to support general health (routine well child/dental care,

immunizations, etc.)

HOW/WHERE DIRECT CARE SERVICES ARE PROVIDED:

The following DSCC programs provide direct health care services:

The Children’s Habilitation Clinic was formerly known as the Center for Handicapped Children. The Clinic provides comprehensive diagnostic services to children with complex disabling conditions and provides ongoing rehabilitation and developmental management to those children to age 21. There are approximately 1600 patient visits completed annually.

The Supplemental Security Income - Disabled Children's Program provides assistance in locating rehabilitative services to children under 16 years of age who are eligible for the Supplemental Security Income (SSI) program. DSCC provides information about and referral to community/state resources, including referrals to Early Intervention, preschool programs, and when appropriate, DSCC Core services.

DSCC Community Clinics – DSCC provides 63 specialty clinics in ten locations throughout the state. These clinics provide local access to specialty care in underserved areas, particularly rural areas of the state.

Specialty Clinics/Programs:

DSCC approves and utilizes specialty programs in the following clinical areas:

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| Cardiac Care including Surgery | Cystic Fibrosis |
| Cleft Lip and Palate | Epilepsy Surgery |
| Cochlear Implantation | Hemophilia |
| Craniofacial Anomalies | Selective Posterior Rhizotomy |

Coordination of Financial Assistance:

Families must maximize the use of insurance benefits, trusts, gifts, legal settlements, or other public or private resources. The rare exception to this practice is for eligible children enrolled in the Early Intervention Program and the IL Comprehensive Health Insurance Program (who are payors of last resort), where DSCC is the secondary payor after private insurance has been utilized.

SPECIALIZED OR UNIQUE DIRECT CARE SERVICES, SPECIAL GRANTS, WORKSHOPS, ETC.:

Contact the Program directly for more information.

II. ENABLING SERVICES

Enabling services are defined as services that allow or provide for access to and the receipt of benefits from an array of basic health care services and includes such things as transportation, translation services, outreach, respite care, health education, family support services, purchase of health insurance, case management, coordination of Medicaid, WIC and education.

ELIGIBILITY CRITERIA FOR ENABLING SERVICES

Age:

Same as “Direct Health Care Services” above.

Residency:

Same as “Direct Health Care Services” above.

Medical:

Same as “Direct Health Care Services” above.

Financial:

Same as “Direct Health Care Services” above. Children do not have to meet financial criteria to receive care coordination or diagnostic services. Additional funds are available through the Friends of DSCC Gift Account, which can assist families in meeting unique, non-recurring needs of the child and/or family that cannot be met through the established Core Program.

ENABLING SERVICES (PROVIDED OR PAID FOR):

DSCC assists families in accessing and receiving services, including basic health care through the Medical Home, specialty medical care, transportation, translation, outreach, health education, and support groups.

Coordination of Care:

Care coordination is a significant program component and is provided for all medically eligible children regardless of eligibility for financial assistance. Professional staff evaluate each child’s condition, and with the family’s participation, develop an Individualized Service Plan, recommend health care providers and facilities, assist with arrangement of health care, and monitor the status of the child and family. Also assist in transition planning and coordinating/maximizing insurance benefits and Medicaid benefits, including application for KidCare.

Excluded Enabling Services:

Custodial services
Educational and developmental services

HOW/WHERE ENABLING SERVICES ARE PROVIDED:

The Core Program is the major focus of DSCC and offers care coordination and cost-supported diagnosis and treatment for children with chronic health impairments determined eligible for program support. DSCC supports non-investigational treatment recommended by physician specialists, such as therapy, medications, specialized equipment, and supplies. Application forms are available on the Core Program page of our website. Through a network of 13 regional offices and 40 satellite offices, over 200 care coordination staff provide enabling services for 24,000 families annually.

Specialty Clinics/Programs:

Same as “Direct Health Care Services” above.

SPECIALIZED OR UNIQUE ENABLING SERVICES, SPECIAL GRANTS, WORKSHOPS, ETC.:

DSCC administers various related programs, which serve children with special needs including:

The Supplemental Security Income/Disabled Children’s Program (SSI/DCP)

SSI/DC Program eligible children are offered assistance to locate and access programs providing needed services including the DSCC program for CSHCN. Additional effort is focused on those children 3-5 years to provide a direct link to those state programs for potential assistance.

The Home and Community-Based Services Medicaid Waiver Program for Technology Dependent/Medically Fragile Children

The Program provides care coordination and support for in-home nursing care of technology-dependent children who would otherwise have to remain in a hospital or skilled nursing facility. In addition medical equipment and supplies, home modifications, respite care, and medical day care needed to care for them in their own home and community rather than a hospital or skilled nursing facility are available. The Division of Specialized Care for Children (DSCC) operates this waiver program on behalf of the Illinois Department of Public Aid (IDPA).

III. POPULATION-BASED SERVICES

Population-based services are defined as prevention services and personal health services that are developed and available for the entire MCH/CSHCN population of the state rather than for individuals on a one-on-one situation. Disease prevention, health promotion, and statewide outreach are major components. Common among these services are newborn screening, lead screening, immunizations, SIDS counseling, oral health, injury prevention, nutrition, and outreach/public education.

POPULATION-BASED SERVICES (PROVIDED OR PAID FOR):

The following population-based services are provided through DSCC: DSCC supports the newborn hearing and genetic screening programs by providing no-cost diagnostic evaluations for families in need of these services.

HOW/WHERE POPULATION-BASED SERVICES ARE PROVIDED:

Not applicable.

SPECIALIZED OR UNIQUE POPULATION-BASED SERVICES, SPECIAL GRANTS, WORKSHOPS, ETC.:

Not applicable.

IV. INFRASTRUCTURE BUILDING SERVICES

Infrastructure building services are defined as services that address the development and maintenance of comprehensive health services systems. Infrastructure building services include: needs assessment, evaluation, planning, policy development, coordination, quality assurance, standards development, monitoring, training, applied research, development of information systems and systems of care (which are family-centered, community-based, etc.), development and maintenance of health services standards/guidelines, training, data and planning systems, etc.

INFRASTRUCTURE BUILDING SERVICES:

As listed in the above paragraph.

HOW/WHERE INFRASTRUCTURE BUILDING SERVICES ARE PROVIDED:

Needs assessment is accomplished every five years. All DSCC Programs undergo evaluation, planning, policy development, coordination, quality assurance, standards development, monitoring, and staff training. The latest program development in these areas has been the “medical home”, including the development of a CME Medical Home Monograph for physicians. DSCC is very active in supporting transition activities that focus on health issues for adolescents. A DSCC web site has been extensively developed that includes both intranet and internet access. Regional family support groups, a Family Advisory Council and a family newsletter (Special Addition) provide families input to our program and information/advocacy development.

SPECIALIZED OR UNIQUE INFRASTRUCTURE BUILDING SERVICES, SPECIAL GRANTS, WORKSHOPS, ETC.:

Illinois is a mentor for other states and territories in their development of medical homes for CSHCN families.

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OUT-OF-STATE SERVICES FUNDED BY THE PROGRAM:

Out-of-state services may be provided if the needed resource is not available in Illinois. Services provided within 25 miles of Illinois borders are considered in-state services.

STATUTORY/REGULATORY AUTHORITY OF THE PROGRAM:

Statutory: Implementing Section 1 of the Specialized Care for Children Act (Ill. Rev. Stat. 1991, ch. 144, par 67.1) [110 ILCS 345/1] and authorized by Section 1 of the University of Illinois Act (Ill. Rev. Stat. 1991, ch. 144, par. 22) [110 ILCS 305/1].

Regulatory: Adopted at 11 Ill. Reg. 3508, effective February 10, 1987; amended at 13 Ill. Reg. 9283, effective June 6, 1989; amended at 14 Ill. Reg. 5136, effective March 22, 1990; amended at 17 Ill. Reg. 1137, effective March 8, 1993; emergency amendment at 17 Ill. Reg. effective January 24, 1994.