



## What Parents Should Know... About Services and Supports for Children with Special Health Care Needs and Their Families

### Finding Your Way

*Almost one in four families with children has at least one child with a special health care need. If you are among them, give your family every advantage by exploring the services and supports designed to help. SD Parent Connection understands and is here to assist you. To identify resources not featured in this Brief, please see our online Family Resource Guide at [www.sdparent.org](http://www.sdparent.org), or request a hard copy of the Guide from SD Parent Connection.*

## Paying for Needed Health Care Services

**Health Insurance** pays for doctor and clinic services, medications, hospital care, and special equipment when you or your family are sick. It also pays for services that keep your family well, such as immunizations for children and adults, routine checkups, counseling and more. Many insurance plans for children now also include dental and vision coverage.

**Medicaid and CHIP** (Children's Health Insurance Program) insurance covers costs for medical, dental and vision care for children and youth under the age of 19 and current residents of South Dakota. Children who are uninsured or have private health insurance may be eligible. Medicaid and CHIP require no — or very reduced — premium payments to cover children and youth in families with limited incomes. Applications can be submitted at any time of the year. Medicaid recipients may be reimbursed for mileage, meals and lodging to a medical provider located in another city. <http://dss.sd.gov/medicaid/recipients/title19transportation.aspx>, 1-866-403-1433.



Individuals and families buy **Private Insurance** by paying monthly premiums. Out-of-pocket expenses (deductibles and co-pays) vary by plan. Some families may have insurance through an employer. Families without insurance may qualify for subsidies in the **Health Insurance Marketplace** to

# Paying for Needed Health Care Services

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make insurance affordable. Open Enrollment in the Marketplace runs from November 1 to January 31. If the deadline is missed, families cannot enroll until the Marketplace re-opens unless there is a special “life event” such as having a baby or losing current health insurance.

South Dakota families can visit [www.sdparent.org](http://www.sdparent.org) (Health Care tab, Insurance) for information and links to learn more, find a local in-person assister, or apply for SD Medicaid/CHIP or insurance through the Marketplace.

**Health KiCC** (Better Health for Kids with Chronic Conditions) provides financial assistance for medical appointments, procedures, treatments, medications and travel reimbursement for children with certain chronic health conditions. Care coordination services are also available on request. To be eligible a child must be under 21 years old, a SD resident, have a chronic medical condition covered by KiCC, and meet financial guidelines. Visit [www.children.sd.gov](http://www.children.sd.gov) to learn more or download/print application material, or call 800-305-3064.

# Special Education and Related Services

Special education is instruction that is specially designed to meet the unique needs of children who have disabilities. IDEA, the Individuals with Disabilities Education Act is the law that gives eligible children with disabilities, regardless of severity, the right to receive a free appropriate public education (FAPE) in the least restrictive environment (LRE).

**Birth to Three Connections** provides services\* for children from birth to age three who have a disability or developmental delay with no cost to families. Birth to Three helps families learn what they can do to help their child. Families and providers work together to create an IFSP (Individual Family Service Plan) that describes services to be provided. Referral to Birth to Three may be made by a doctor or other provider but is not required. Any family with a concern about their child may directly contact Birth to Three Connections at 800-305-3064. Learn more at [www.doe.sd.gov/oess/Birthto3.aspx](http://www.doe.sd.gov/oess/Birthto3.aspx).

## Early Childhood (Preschool), K-12, Post School (Age 18-21) Programs

Special education and related services\*\* are provided in public schools at no cost to parents and can include special instruction in the classroom, at home, in hospitals or institutions, or in other settings. Qualifying children have an IEP (Individual Education Program/Plan) that describes the specially designed instruction that will be offered and may include special services and assistance in the school setting.

A family who believes their child may have a

\* **Services** are provided in the child’s natural environment, usually in the home or childcare setting, and may include assessments, audiology, assistive technology, family training and counseling, home visits, health services, medical services for evaluation, nursing, nutrition, occupational therapy, physical therapy, psychological services, social work services, service coordination, special instruction, speech and language, transportation, and vision services.

\*\* **Related Services:** Include early identification and assessment of disabilities, medical services for diagnostic or evaluation purposes, transportation, speech/language and audiology services, interpreting services, psychological services, physical and occupational therapy, recreation/therapeutic recreation, counseling, orientation and mobility services, rehabilitation counseling, school health and school nurse services, social work services in schools, and parent training and counseling.

# Special Education and Related Services

disability (or developmental delay for ages 3-5) can request an evaluation for special education services from their local school to determine their child's eligibility. South Dakota Parent Connection (SDPC) has created several resources to support families in their evaluation requests: *Parent Brief - What Parents Should Know About Evaluations and Re-Evaluations*; *Checklist for Evaluation Requests*; *Sample Letter for Requesting an Evaluation*; and the booklet *Dare to Dialogue...Reach Yes!* These resources can be found on the SDPC website, or contact us to request hard copies and/or for assistance.

## Section 504 of the Rehabilitation Act of 1973

Students who do not qualify for IDEA protections may be eligible for special education and related services through a 504 Plan due to the Act's broad definition of disability. Under Section 504, FAPE means providing regular or special education and related aids and services designed to meet the student's individual educational needs as adequately as the needs of nondisabled students are met. Please refer to our *Parent Brief...What Parents Should Know About Supporting Students Through 504 and Health Plans* or online training *The Ins and Outs of a 504 Plan* (<http://www.sdparent.org/web/index.php?siteid=2825&pageid=22958>) for more information.



**South Dakota School for the Blind and Visually Impaired, Direct Services/Outreach Services** offers services at no cost for children (birth through 21 or high school graduation) with vision loss who are SD residents. Services can be requested by parent/guardian, school, or other service or medical provider. SDSBVI offers direct educational services in Aberdeen and other designated locations; an optional residential program for those students better served in such an environment; a resource center for information about vision loss, educational materials, methods and equipment; consultative services to develop appropriate education programs; supplementary services, including summer programming to reinforce educational growth, provide for special skills training and assist students in understanding their vision loss and their own abilities. SDSBVI provides comprehensive multidisciplinary evaluations for blind, visually impaired and deaf/blind students statewide. Outreach Consultants provide support services to parents and school districts. Outreach Transition Service is a joint effort of SDSBVI and Services to the Blind and Visually Impaired and is available to students aged 14 and older. <http://sdsbvi.northern.edu>, 888-275-3814 or 605-626-2580 (Voice/TTY).



**South Dakota School for the Deaf Outreach Program, Mobile Hearing Lab/Audiology Services** offers services at no cost for children (birth through 21 or high school graduation) with hearing loss who are SD residents. Services can be requested by parent/guardian, school, or other service or medical providers. Services may include assignment of an Outreach Consultant to your child/family; home-based early intervention; school-based interventions; diagnostic audiological evaluations; comprehensive multi-disciplinary evaluations; orientation and services related to hearing aid, cochlear implant, FM systems, interpreters, and other technology. [www.sdsd.sdbor.edu](http://www.sdsd.sdbor.edu), 605-367-5200, ext 100 (Voice/TTY).

# State Programs



**Advanced Special Needs Childcare Assistance** program helps eligible families maintain employment when there are challenges in obtaining quality, affordable child care for their child (under age 19) with special needs. These families often do not meet eligibility requirements of the regular child care assistance program. A limited number of slots are available statewide at any one time; eligible families will be placed on a waiting list until an opening occurs. 800-227-3020.

**Child Care Services** helps pay for child care costs for low income families so they can work or attend school. <http://dss.sd.gov/childcare/childcareassistance/>, 800-227-3020.

**Child Safety Car Seat Distribution Program** provides car seats and booster seats to income eligible families across South Dakota. Specialized car seats for children with special health care needs are provided with no family income guidelines. Specialized seats may also be available for short-term loan at no cost. <http://dss.sd.gov/childcare/childsafetysat/>, 800-227-3020.

**Cochlear Implant Program** provides financial assistance to an eligible individual who is uninsured or to help offset the deductible or coinsurance for an individual with an insurance plan that covers cochlear implants. The program provides funding for the cost of the implant surgery for one ear or both ears, one or two implant devices, surgeon fee, hospital fee, the initial mapping and a maximum of 12 follow up mappings within one year post surgery. [http://dhs.sd.gov/drs/cochlear\\_implant/cochlear-implant.aspx](http://dhs.sd.gov/drs/cochlear_implant/cochlear-implant.aspx), 800-265-9684.

**Disabled Children's Program** is for eligible families of children who have medically fragile conditions requiring skilled nursing care in a medical facility if they were not being cared for at home. <http://dss.sd.gov/medicaid/generalinfo/medicalprograms.aspx>, 877-899-5612.



**Establishment Program** helps families or friends of adults with developmental disabilities who reside in South Dakota pay legal costs up to \$500 associated with establishing a guardianship or conservatorship. <http://dhs.sd.gov/gdn>, 800-265-9684.

**Family Support 360** is designed to assist families who have a child with a developmental disability, age birth to 22, living in the home. A flexible pool of limited funds is available to eligible families, regardless of income,

# State Programs



for the purchase of services or supports that may not otherwise be available (incontinence supplies, therapeutic devices, home and vehicle modifications, other needs). Once eligibility has been established, a family will receive support through the Statewide Family Support Program while waiting for the opportunity to transfer to the Family Support 360 Waiver. The Family Support 360 Waiver provides service coordination, a wide array of services, and potential access to Medicaid for the eligible child. The Family Support 360 Waiver allows the family to choose service providers and direct the services they receive. <http://dhs.sd.gov/dd/family/index.aspx>, 800-265-9684.

**Hearing Aid Assistance Program** helps purchase hearing aids and associated ear molds for South Dakota children, younger than 19, with progressive or permanent hearing loss who would benefit from hearing aids. The individual must not have received a hearing aid from this program or SD Medicaid within three years prior to the date of application. The program is open to families with household income of less than 400 percent of federal poverty guidelines and operates on a sliding fee schedule, contributing from half to the entire cost for purchasing hearing aids and associated ear molds. <http://dhs.sd.gov/drs/deafserv/deaf.aspx>, 800-265-9684.

**Premium Assistance Program**, SD Department of Social Services may provide financial assistance for private insurance premiums to Medicaid eligible children and adults on a case-by-case basis. 888-828-0059.



**Respite Care Program** helps families pay for respite services that families set up. Respite can occur in out-of-home or in-home settings, providing a temporary break for caregivers and families with a child(ren) or adult with disabilities or chronic illnesses. <http://dhs.sd.gov/dd/respite/index.aspx>, 800-265-9684.

**South Dakota Council on Developmental Disabilities** provides funds to assist people with developmental disabilities and/or their family members to attend in-state conferences, training events, committees, and other similar activities or to attend out-of-state conferences or training events when there is nothing similar held in South Dakota. <http://dhs.sd.gov/ddc/>, 605-773-6369.

**Telecommunication Equipment Distribution Program** assists people who have difficulty communicating over the telephone because of hearing loss or speech disability. A variety of smart devices (iPad, iPhone) and specialized phone equipment is available to qualified residents of South Dakota at no cost. (Amplified phones, loud ringers, light flashers, ring signalers w/bed shaker, TTY's, captioned phones). [www.sdrelay.com](http://www.sdrelay.com), 800-265-9684.

# Community Supports

**Independent Living Centers** are located throughout South Dakota and provide a wide variety of supports to enable individuals with disabilities, including children, to remain in their homes. Supports may include housing modifications, adaptive equipment, information and referral, peer support groups, summer youth transition programs, and more. Eastern South Dakota is served by Independent Living Choices ([www.ilcchoices.org](http://www.ilcchoices.org), 800-947-3770). Western South Dakota is served by Western Resources for Independent Living ([www.wrill.org](http://www.wrill.org), 888-434-4943). Native American Advocacy Project ([www.lakotanaap.org](http://www.lakotanaap.org), 605-775-2147) provides independent living services to people with permanent disabilities who live in the Tribal Nations of South Dakota.



## Conflict Free Case Management

The State of South Dakota recently adopted a conflict free case management policy. Direct supports – such as residential, vocational, nursing, and employment supports – will continue to be provided by the Community Support Providers chosen by the participant. Independent conflict-free case managers chosen by the individual, family or assigned by the state work with the Individualized Support Plan (ISP) team to develop an ISP using a standardized ISP format that ensures a person-centered approach to planning. The Conflict Free Case Manager makes sure the participant is receiving supports and services as planned and that personal outcomes are met. Although the providers of conflict-free case management have changed, high-quality case management will continue. <http://dhs.sd.gov/dd/cfcm/default.aspx>.

# Social Security Administration (SSA) Benefits

## Supplemental Security Income

**(SSI)** is a Federal program that provides monthly income to children with qualifying disabilities in low income families (Child Benefits) and adults with qualifying disabilities with low incomes (Adult Benefits). In South Dakota, SSI recipients will also receive Medicaid. Child applicants may not meet income and resource limitations due to required

The Benefit Eligibility Screening Tool (BEST) will help you find SSA benefits you may be eligible for and explain how to qualify and apply.

<http://ssabest.benefits.gov/>

Compassionate Allowances initiative allows SSA to accelerate processing of SSI and SSDI applications for many severe medical conditions.

[www.ssa.gov/compassionateallowances/conditions.htm](http://www.ssa.gov/compassionateallowances/conditions.htm)

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# SSA Benefits

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reporting of all household income. However, once a youth becomes an adult at age 18, only the income and resources of the youth are considered, regardless of where they live or with whom. [www.socialsecurity.gov/disabilityssi/ssi.html](http://www.socialsecurity.gov/disabilityssi/ssi.html).

**Social Security Disability Income (SSDI)** provides monthly income for adults who became disabled in childhood and are eligible for benefits if a parent is deceased, or receiving retirement or disability benefits. SSA considers this a “child” benefit because it is paid on a parent’s Social Security earnings record. The parent is “insured” as a result of length of work history and Social Security (payroll) tax payments. The “adult child”—including an adopted child, or, in some cases, a stepchild, grandchild, or step grandchild—must be unmarried, age 18 or older, and have a disability diagnosed before age 22.

## SSI at Age 18

Social Security determines disability for adults (18 years and older) by different standards than those used for children. Receiving SSI Children’s benefits is not a guarantee of qualifying as a disabled individual under the SSI adult standards. Adult eligibility is determined by the ability to be substantially and gainfully employed while child disability is determined by a child’s functional ability. For children receiving Social Security benefits, families should anticipate a re-determination process at the time of turning 18 years of age, using the adult criteria. An adult application for Social Security benefits can be initiated at any time following the 18th birthday or not more than three months before the age of 18.

# Private Organizations and Foundations

Supports may be available at the local, state and national levels to help families meet the needs of their children with special health care needs. Please refer to the Family Resource Guide or contact SD Parent Connection to identify options available to your family.

**Communication Services for the Deaf (CSD)** provides support services to individuals who are Deaf, hard of hearing or speech impaired. This ranges from Deaf or hard of hearing individuals, Deaf children with hearing parents, Deaf parents with hearing children, parents of children that are non-verbal and in need of a mode of communication, and more. Programs are at no/reduced cost to the consumers, such as sign language instruction, advocacy, peer support, information and referral, communication assistance, and trainings. [www.csd.org](http://www.csd.org). Aberdeen 866-246-5759, Rapid City 888-304-2311, Sioux Falls 866-246-5759.

**NeedyMeds, Inc.** maintains current information about many sources of medication and health care cost assistance that anyone can use without registering or entering any personal data. [www.needymeds.org](http://www.needymeds.org).

**Partnership for Prescription Assistance (PPA)** is a free and confidential program offering a single point of access to programs that offer more than 2,500 brand-name and generic prescription medicines for free or nearly free. Includes more than 40 assistance programs that focus on the health care needs of children. <https://www.pparx.org/>.

**South Dakota Advocacy Services** provides information, referrals and representation to help protect the rights of persons with disabilities. [www.sdadvocacy.com](http://www.sdadvocacy.com), 800-658-4782 (Voice/TTY).

# Tips for Successful Program Applications

- Applying for programs is often frustrating. Be persistent, but courteous. Be firm, but respectful. Express appreciation for assistance provided.
- Before applying, understand the application and eligibility guidelines and the terminology within that system. Words or phrases may have different meanings between systems. If you don't understand or are unsure, ask questions until you do.
- Provide complete and appropriate documentation so the "evidence" you submit matches the rules of the program. Programs are not likely to process applications if required documentation is missing or different than what the program requires.
- Include current phone numbers and email addresses to ensure you can be reached. Your application will be discarded if they cannot contact you.
- Sign and date the application before submitting, and check to see that all required documents are included.
- Many programs require documentation from a third party, such as a doctor, therapist, school, etc. Share with these providers/supports that you are applying for "x" program and they may be contacted to provide "y" for your application. Providers will appreciate the advance notice and will be prepared to provide the necessary information.
- If you receive a program denial, don't take it personally. Question policies, procedures and process — but never motives. Families can ask questions and ask for documentation related to:
  - How did the program arrive at the decision?
  - What steps can be taken to trigger re-consideration of the denial?
  - What is the process to appeal the denial and related time frames?
- An initial denial may well be approved with clarification, submission of additional information, or on appeal. Persistence is often the key to success.



## You Are Not Alone

SD Parent Connection exists to connect families of children and youth with disabilities or special health needs to resources, information and training in an environment of support, hope and respect.

Call us at 1-800-640-4553, visit us at our Sioux Falls or Rapid City locations, or connect with us at [www.sdparent.org](http://www.sdparent.org) or [m.sdparent.org](http://m.sdparent.org).

We look forward to working with you!