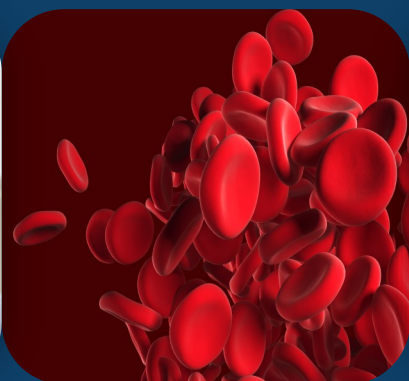


NORTH  
**Dakota** | Health  
Be Legendary.™

**Metabolic Disorders  
Resource Booklet**



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## **Disclaimer**

The content within this booklet is for informational purposes only. It is not intended to be a substitute for professional medical advice. Families are encouraged to discuss the information in this booklet with their child’s doctor or other health care providers.

# Specialty Health Services

For many children with metabolic disorders, evaluation by an experienced team of professionals is necessary for optimal treatment. Families are an essential partner to the team as they are the principle caregiver and the center of strength and support for the child. The links below provide access to information on many metabolic disorders and their diagnosis, management or treatment: [ghr.nlm.nih.gov/condition](http://ghr.nlm.nih.gov/condition) or [nbs.health.nd.gov](http://nbs.health.nd.gov).

## Clinics and Programs

Special Health Services (SHS) funds a metabolic disorders clinic for children with Phenylketonuria (PKU), Maple Syrup Urine Disease (MSUD), Medium-chain acyl-CoA dehydrogenase (MCAD), and other metabolic disorders in Fargo, N.D. This SHS supported clinic provides multidisciplinary team evaluations where families have an opportunity to see many different providers in one place at one time. Reports generated from the clinic visit include recommendations to help direct care for the coming year. All children who might benefit are eligible to attend with no direct cost to the family. For more information, review the following link: [https://www.health.nd.gov/sites/www/files/documents/Files/HSC/SHS/SHS\\_Clinic\\_Directory.pdf?ver=2](https://www.health.nd.gov/sites/www/files/documents/Files/HSC/SHS/SHS_Clinic_Directory.pdf?ver=2)

Clinics make a positive difference in children's overall care. Families report that clinics provide:

- Information, education and reassurance
- Diagnostic evaluation and treatment
- Coordinated/comprehensive care
- Follow-up and monitoring
- Access to specialty medical care

### Metabolic Disorders Clinic

The clinics are held multiple times per year. Support for family travel and lodging expenses may be available.

Sanford Broadway Building  
737 North Broadway  
Fargo, N.D. 58102  
701-234-6600  
Toll free: 800-828-2901, #3 Option

### Metabolic Food Program

The Metabolic Food program provides medical food and low-protein modified food products to individuals with PKU and MSUD. For more information, contact SHS at 701-328-2436 or toll-free at 800-755-2714.

## Other Low-Protein Food and Formula Assistance

Formula and low-protein food companies may offer varying degrees of assistance. The following is a list of examples, but not representative of all companies.

- Cambrooke Foods offers assistance with low-protein food products through their Cambrooke Care program. An application is available at [cambrooke.com/included/docs/cambrookecare\\_app\\_form.pdf](http://cambrooke.com/included/docs/cambrookecare_app_form.pdf).
- Abbott-Nutrition may offer assistance to individuals that are not covered by a public or private entity. They do have financial criteria, but do not limit according to age. To learn more go to [abbottnutrition.com](http://abbottnutrition.com) or call toll-free at 800-227-5767.
- Nutricia offers personalized assistance obtaining formula coverage through their Nutricia Navigator program. To learn more go to <http://www.medicalfood.comreimbursementga=2.151019961.162338250.1622723671-1817217120.1605020520> or call 1-800-365-7354.

## Phenylalanine (Phe) Testing

Every baby born in North Dakota is required by state law to have a newborn blood spot screening test, which includes testing for specific hereditary and genetic disorders. Phenylketonuria (PKU) is one of the disorders that may be identified by this testing. Newborns with PKU will need to have routine lab work drawn and will be monitored by a metabolic specialist. The ND Department of Health has a contract with Sanford Health to monitor patients with PKU who reside in ND or are a patient of the designated specialist from Sanford Health. For additional information on PKU monitoring or to request testing supplies, contact the Sanford Medical Genetics Clinic at 701-234-2362.

For a complete listing of the disorders included on the newborn blood spot screening panel, visit the ND Newborn Screening Program website:

[nbs.health.nd.gov/materials-resources/fact-sheets-disorders](http://nbs.health.nd.gov/materials-resources/fact-sheets-disorders)

## Insurance

The cost of special metabolic formulas and special low-protein foods may be reimbursed by insurance companies. State law mandates insurance policies cover medical food and low-protein modified food products that have been determined medically necessary by a physician for the treatment of inherited metabolic disease.

## Assistance

SHS can pay for special formula when children birth to age 21 are medically and financially eligible for the Financial Coverage program. For more information, call 800-755-2714.

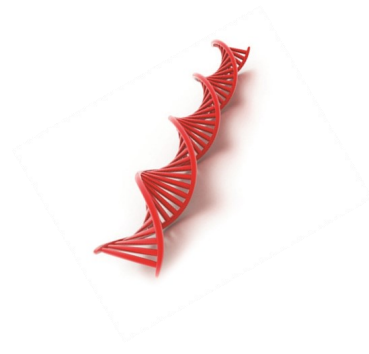


# Genetic Services

Genetic testing is used to identify DNA changes associated with specific medical conditions. Genetic testing can help determine whether a person has a genetic disease, whether it has been inherited, and the chance for future children or other family members to have the same condition.

## Sanford Children's Broadway Clinic

737 N. Broadway  
Fargo, N.D. 58102  
Phone: 701-234-2362  
[sanfordhealth.org/medical-services/genetics](http://sanfordhealth.org/medical-services/genetics)



## Sanford Health Genetic Counseling

209 North 7th St.  
Bismarck, N.D. 58501  
Phone: 701-323-8030

Women's Medical Center  
414 North 7th St.  
Bismarck, N.D. 58501  
701-323-5870

[sanfordhealth.org/medical-services/genetics/genetic-counseling](http://sanfordhealth.org/medical-services/genetics/genetic-counseling)

## Informed Medical Decisions (telehealth genetic counseling services)

North Dakota Contact:  
Marie Schuetzle, MS, CGC Senior Genetic Counselor  
Phone: 800-975-4819  
Fax: 800-930-0961  
[informeddna.com](http://informeddna.com)

### Health Care Providers

Metabolic disorders can often best be managed by a metabolic clinic team. In North Dakota, care providers may include:

- Child Psychologist
- Education Specialist
- Licensed Independent Clinical Social Worker
- Nurse Clinic Coordinator
- Pediatric Geneticist
- Prenatal/Pediatric Nutrition Specialist
- Medical Social Worker

# Additional Resources

## Anne Carlsen Center

The Anne Carlsen Center offers a rich tradition of empowering individuals with disabilities and their families. Their experienced staff provides compassion, training, services and support in homes and communities across North Dakota. On the Jamestown campus, they meet the educational, residential and therapeutic needs of children and young adults with autism, behavior disorders, medical fragility and other developmental disabilities. They also provide services in the home through customized support for individuals from birth to age 21. In addition, through their community-based services (i.e., in-home support and community day support), Anne Carlsen accommodates individuals of all ages, including adults. For more information about services in the Dickinson location, call 701-934-1144 or visit: [annecarlsen.org](http://annecarlsen.org).

**Bismarck** (also covering Dickinson)  
1929 N. Washington St., Suite GG  
Bismarck, N.D. 58501  
701-751-3732  
800-201-8672

**Jamestown**  
701 3rd St. NW  
Jamestown, N.D. 58402  
701-252-3850  
800-568-5175

**Fargo**  
4152 30th Ave. S., Suite 102  
Fargo, N.D. 58104  
701-364-2663  
800-201-8672

**Minot**  
1408 20th Ave. SW,  
Suite 7  
Minot, N.D. 58701  
701-858-0009

**Grand Forks**  
2016 South Washington St.  
Grand Forks, N.D. 58201  
701-757-4200  
888-815-3770

**Devils Lake**  
218 4th St. NW  
Devils Lake, N.D. 58301  
701-662-6324

**Bottineau**  
1 Winter Park Road  
Bottineau, N.D. 58318  
701-263-4556

## Early Intervention (Infant Development)

This is a service designed to help families with children from birth to age three with disabilities and/or developmental delays. The goal of this program is to support the child and their family in gaining skills and fully participating in their natural environment. By partnering with families, ND Early Intervention provides them with the tools and support they need to help their child be successful. Qualifying families have access to a wide array of therapeutic professionals, as well as a Service Coordinator (DD Program Manager) and an Experienced Parent. Anyone, including family members, can refer a child for a free developmental evaluation, with eligibility based on the following criteria:

- Displays a 50 percent delay in any area of development (cognition, communication, motor, self-help or social emotional skills).
- Displays a 25 percent delay or more in any two areas of development.
- Has a diagnosis or disability that impairs typical development.
- Has a significant health condition that puts them at high risk for developmental delays.

Another component to ND Early Intervention is Right Track. Right Track provides a variety of services to families, which include developmental screenings, referrals to community resources, serving as a resource to parents, etc. To make a referral, or to learn more, call the Developmental Disabilities Division at 800.755.8529 or visit: [nd.gov/dhs/services/disabilities](http://nd.gov/dhs/services/disabilities).

## Supplemental Security Income (SSI)

SSI provides monthly payments for children who meet disability and financial eligibility requirements. For more information, contact the Social Security Administration at 800-772-1213 or visit [ssa.gov](http://ssa.gov).

## Women, Infants and Children (WIC)

WIC provides nutritious foods, offers information about how to feed your family, and helps you participate in other important health programs. Pregnant women, breastfeeding women and children up to age 5 who meet WIC's liberal income guidelines are eligible to participate. For more information, contact 800-472-2286 or your county WIC office as listed in the phone book. Visit [ndhealth.gov/wic](http://ndhealth.gov/wic) for additional details.



# Family Support Services

## Child Care Assistance Program

This program provides financial assistance to low-income families for child care costs.

North Dakota Department of Human Services  
600 East Boulevard Ave., Dept. 325, Bismarck, N.D. 58505  
Phone: 701-328-2332  
Toll-Free: 800-755-2716  
[nd.gov/dhs/services/financialhelp/childcare.html](http://nd.gov/dhs/services/financialhelp/childcare.html)

## Child Care Aware

Child Care Aware provides assistance locating child care and other related services. Call Child Care Aware at 800-997-8515 or visit [ndchildcare.org](http://ndchildcare.org) for more details.

**Bismarck:** 701-530-2525  
**Fargo:** 701-476-6820  
**Grand Forks:** 701-787-7755  
**Jamestown:** 701-252-0350

## Developmental Disabilities Division

The Developmental Disabilities Division within the ND Department of Human Services provides services to North Dakota citizens of all ages with developmental disabilities.

Developmental Disabilities Division  
Phone: 800-755-8529  
[nd.gov/dhs/services/disabilities](http://nd.gov/dhs/services/disabilities)



## Family Voices of North Dakota

Family Voices of ND is a health care information and education center, which includes the Parent to Parent Project, a program that offers emotional support to families. For more information, call 701-493-2634 or 888-522-9654, or visit [fvnd.org/site/](http://fvnd.org/site/) for more details.

## ND Federation of Families for Children's Mental Health

Federation of Families provides support and advocacy for children's mental health. Call 701-222-3310 or visit [ndffcmh.org](http://ndffcmh.org) for more information.

## Legal Services of North Dakota

Legal Services of ND provides legal assistance for a variety of matters to low income and elderly North Dakotans.

418 East Broadway, #7  
Bismarck, N.D. 58501  
Phone: 701-258-4270 or 800-634-5263  
[legalassist.org](http://legalassist.org)

## National Alliance on Mental Illness North Dakota

This organization offers meetings and training opportunities throughout North Dakota that focus on education and support for consumers, families and friends.

2242 Springbrook Ct.  
Grand Forks, N.D. 58201  
Phone: 701-746-5380  
<https://www.nami.org/Find-Your-Local-NAMI/Affiliate?state=ND>

## Center for Patient Information & Resources (CPIR)

CPIR is an information clearinghouse that provides free information about disabilities and disability-related issues. For more information, call 973-642-8100 or visit [parentcenterhub.org](http://parentcenterhub.org).



## Pathfinder Services of ND

Statewide parent training is offered and information provided to help families of children and youth with learning difficulties.

Town and Country Center  
1015 S. Broadway, Suite 42  
Minot, N.D. 58701  
Phone: 701-837-7500 or 800-245-5840  
[pathfinder-nd.org](http://pathfinder-nd.org)

## Protection and Advocacy Project (P&A)

P&A advocates for the legal rights of North Dakotans with disabilities.

400 East Broadway, Suite 409  
Bismarck, N.D. 58501  
Phone: 701-328-2950 or 800-472-2670  
Fax: 701-328-3934  
[ndpanda.org](http://ndpanda.org)

## Regional Center for Independent Living (RCIL)

RCIL provides services that help young people with disabilities with transition from home and school to the work place and independent living. Visit [rcil.org](http://rcil.org) for more information.

### **Dakota Center for Independent Living**

3111 East Broadway  
Bismarck, N.D. 58501  
701-222-3636 or 800-489-5013

### **Dakota Center for Independent Living**

26 First St. E  
Dickinson, N.D. 58601  
701-483-4363

### **Freedom Resource Center**

2701 9th Ave. S., Suite H  
Fargo, N.D. 58103  
701-478-0459 or 800-450-0459

### **Independence Inc.**

2000 E. Burdick Expressway  
Minot, N.D. 58701  
701-839-4724 or 800-377-5114

## Ronald McDonald House Charities

Ronald McDonald House Charities provides a temporary residence near the medical facility where family members can sleep, eat, relax and find support from other families in similar situations. In return, families are asked to make a donation, but if that isn't possible, the stay is free.

### **Bismarck**

609 North 7th St.  
Bismarck, N.D. 58501  
701-258-8551  
[rmhcbismarck.org](http://rmhcbismarck.org)

### **Fargo**

1330 18th Ave. S.  
Fargo, N.D. 58103  
701-232-3980  
[rmhcfargo.org](http://rmhcfargo.org)

# Information and Referral Services

## Special Health Services (SHS)

The mission of the Division of Special Health Services is to promote a system of care and services that improves the health and well-being of individuals with special health care needs and their families. Cross-cutting implementation strategies at the heart of all SHS programs include:

- Care Coordination
- Collaboration
- Data-informed Decisions
- Information and Education

## Programs and Services

**Coordinated Services:** Provides services and resources that support coordinated management of specific chronic health conditions.

**Financial Coverage Program:** Helps families pay for medical services for eligible children, youth, and young adults who require specialty care to diagnose and treat their chronic health conditions.

**Newborn Screening and Follow-up Program:** The goal of this program is to identify conditions at an early age when treatment and intervention can prevent health problems, support early development, and save lives.

**Children with Special Health Care Needs System Enhancement:** Improves health outcomes of Children with Special Health Care Needs (CSHCN) by advancing a quality, comprehensive system of care that promotes the healthy development and well-being of children and their families.

North Dakota Department of Health  
State Capitol – Judicial Wing  
600 East Boulevard Ave., Dept. 301  
Bismarck, N.D. 58505  
Phone: 701-328-2436  
Toll-free: 800-755-2714  
Relay TDD: 800-366-6888  
<https://www.health.nd.gov/Youth/special-health-services>

## Human Service Zones

Human Service Zones, formerly County Social Services, administer economic assistance and social service programs. To inquire about assistance, please contact your local Human Service Zone, or visit [nd.gov/dhs/locations/countysocialserv](https://nd.gov/dhs/locations/countysocialserv).

## Pediatricians and Family Doctors

All children benefit from a medical home. A medical home is not a building, but rather an approach to providing comprehensive medical care. In a medical home, a physician or other medical provider works in partnership with the family/patient to assure that the medical and non-medical needs of the child/youth are met. Through this partnership, medical providers can help families access and coordinate specialty care, educational services, out-of-home care, family support and other public and private community services that are important to the overall health of the child and family. Contact SHS at 701-328-2436 for a list of pediatric doctors who practice in North Dakota.

## Public Health

Local public health units provide a variety of services such as immunizations, tobacco use prevention, high blood pressure screening, injury prevention screening, blood lead screening, Early and Periodic Screening Diagnosis & Treatment, home visits, high-risk infant follow-up, general child health services, community wellness programs, and school health screenings. Visit [ndhealth.gov/localhd](https://ndhealth.gov/localhd) for details.



# Organizations Statewide

## American Heart Association, North Dakota Affiliate

The American Heart Association (AHA) provides comprehensive information for parents of a child with a congenital heart defect. The AHA helps prepare parents for the medical and surgical treatments their child may require.

1005 12th Ave. SE  
Jamestown, N.D. 58401  
800-437-9710  
[heart.org](http://heart.org)

## ND Chapter - March of Dimes Birth Defects Foundation

March of Dimes fights for the health of all moms and babies by supporting research lead programs and providing education and advocacy so that every baby can have the best possible start.

1712 Main Ave., Suite 101  
Fargo, N.D. 58103  
Phone: 701-235-5530  
[marchofdimes.org/northdakota](http://marchofdimes.org/northdakota)



## ND Center for Persons with Disabilities

NDCPD provides service, education, and research which empowers communities to welcome, value and support the well-being and quality of life for people of all ages and abilities.

Minot State University  
500 University Ave. W.  
Minot, N.D. 58707  
Phone: 800-233-1737  
[ndcpd.org](http://ndcpd.org)



## Project HERO

Project HERO provides unused medical supplies and donated durable medical equipment to those in need. Project HERO works with several agency and healthcare partners to redistribute viable medical products to the medically fragile and financially challenged.

5012 53rd St. S., Suite C  
Fargo, N.D. 58104  
701-212-1921  
[herofargo.com](http://herofargo.com)



## Easter Seals Goodwill ND, Inc.

Easter Seals Goodwill services include, but are not limited to, respite, or relief care; personal care services and domestic homemaker services; equipment loan; advocacy for individuals with disabilities; and information and referral. Visit [esgwnd.org](http://esgwnd.org) for more information.

### Dickinson

2125 Sims St.  
Dickinson, N.D. 58602  
701-264-1060  
866-895-1587

### Fargo

3333 7th Ave. N.  
Fargo, N.D. 58102  
701-237-9908  
866-895-1588

### Grand Forks

3651 South Washington St.  
Grand Forks, N.D. 58201  
701-772-0704  
866-876-1015

### Bismarck-Mandan

1031 Interstate Ave.  
Bismarck, N.D. 58503  
701-751-0863  
800-247-0698

### Jamestown

402 14th Ave. NE #1  
Jamestown, N.D. 58401  
701-251-1446  
866-897-6004

### Mandan

211 Collins Ave.  
Mandan, N.D. 58554  
701-663-6828

### Minot

800 12th Ave. SW  
Minot, N.D. 58701  
701-839-4121  
866-895-1589



## North Dakota Assistive

Services include information and referral, training, technical assistance to systems and individuals, equipment loan library, outreach activities, a link between state and private entities, resource development, alternative loan program and dissemination of assistive technology materials based on consumer input. Visit [ndassistive.org](http://ndassistive.org) for more information.

### Fargo

3240 15th St. S., Suite B  
Fargo, N.D. 58104  
701-365-4728 or  
800-895-4728

### Mandan

2401 46th Ave. SE, Suite 203  
Mandan, N.D. 58554  
701-258-4728 or  
800-895-4728

## Shriners Hospitals for Children—Twin Cities

Shriners Hospitals for Children provides care for children (age 17 and younger) with orthopedic problems and burns. Evaluation clinics are offered throughout North Dakota.

Shriners Hospital for Children –Twin Cities

Phone: 612-596-6100

Patient referral line: 800-237-5055

[shrinershospitalsforchildren.org/minneapolis](http://shrinershospitalsforchildren.org/minneapolis)



**Shriners Hospitals**  
for Children™

## The Arc of North Dakota

The Arc is a member and volunteer-driven nonprofit organization that offers advocacy, education and family support to children and adults with intellectual disabilities and related developmental disabilities and their families.

### Bismarck

The Arc of Bismarck  
1500 E. Capitol, Suite 203

Bismarck, N.D. 58501

Phone: 701-222-1854

[thearcofbismarck.org](http://thearcofbismarck.org)

### Grand Forks

The Arc, Upper Valley, Inc.  
2500 DeMers Ave.

Grand Forks, N.D. 58201

Phone: 701-772-6191

[thearcuppervalley.org](http://thearcuppervalley.org)

### Dickinson

The Arc of Dickinson, Inc.  
653 19th St. W

Dickinson, N.D. 58601

Phone: 701-483-4272

[arcdickinson.org](http://arcdickinson.org)

### Valley City

The Arc of Barnes County  
141 2nd St. NE

Valley City, N.D. 58072

Phone: 701-845-4189

### Fargo

The Arc of Cass County  
215 North University Drive

Fargo, N.D. 58102

Phone: 701-293-8191

[arccassnd.org](http://arccassnd.org)

### Bowman

Little Missouri Arc  
403 2nd Ave. SE

Bowman, N.D. 58623

Phone: 701-523-3330



*For people with intellectual  
and developmental disabilities*



# Libraries

## **FirstLink of North Dakota**

Phone: 701-235-7335 or 2-1-1

Textline: Text your zip code to 898211

Youth Line: text ND4ME to 898211

<https://myfirstlink.org/>

## **North Dakota Center for Persons with Disabilities**

500 University Ave. W, Minot, N.D. 58707

Phone: 701-858-3580 or toll-free 800-233-1737

[ndcpd.org/](http://ndcpd.org/)

## **North Dakota State Library**

604 East Boulevard Ave., Bismarck, N.D. 58505

Phone: 701-328-4622 or toll-free 800-472-2104

[library.nd.gov](http://library.nd.gov)

## **Pathfinder Services of North Dakota Library**

Phone: 701-837-7500 or toll-free 800-245-5840

[pathfinder-nd.org](http://pathfinder-nd.org) \*Click on Resources link on top right of page

## **Prevention Resource and Media Center**

Topics in mental health, substance abuse, aging and disabilities.

1237 W Divide Ave., Suite 1D, Bismarck, N.D. 58501



# Education

## Head Start

Head Start and Early Head Start are comprehensive child development programs. Regular Head Start programs are for children ages three and four. Some communities offer a program specifically for families with children younger than three and pregnant women. A variety of services are provided through Head Start programs including health, education, parent involvement, family literacy, social services and services for children with disabilities.

Head Start State Collaboration Office

Phone: 701-328-1640

<https://www.nd.gov/dpi/education-programs/early-childhood-education/head-start>

## School Nursing

The purpose of school nursing is to support the educational process by contributing positively and significantly to the health, health attitudes and health behaviors of today's children, and consequently, tomorrow's adults. Contact the North Dakota Department of Health at 701-328-2436 or more details.

## Special Education

It is important to locate and identify children who are in need of special services as early as possible. Screening and assessment opportunities offered at school help identify possible areas of difficulty that could interfere with a child's learning or academic performance. Some children with disabilities may require special education services to address their unique educational needs. Contact the North Dakota Department of Public Instruction at 701-328-2277 or your local special education unit. Visit [nd.gov/dpi](http://nd.gov/dpi) for more information.

## Pathfinder Services of ND

Pathfinder Services of North Dakota provides statewide parent training and information to help families of children and youth with learning difficulties.

1015 S. Broadway, Suite 42

Minot, N.D. 58701

Phone: 701-837-7500 or 800-245-5840

[pathfinder-nd.org](http://pathfinder-nd.org)

# Health Care Coverage Options

## Medical Coverage

Medicaid provides comprehensive medical, dental and vision coverage to North Dakota children and adults through a variety of coverage programs and waivers.

600 East Boulevard Ave., Dept. 325  
Bismarck, N.D. 58505  
Phone: 701-328-7068 or 800-755-2604  
Email: [dhsmed@nd.gov](mailto:dhsmed@nd.gov)  
[nd.gov/dhs/services/medicalserv/medicaid](http://nd.gov/dhs/services/medicalserv/medicaid)



## Children with Disabilities Medicaid Coverage

This program allows qualifying children with disabilities to buy into Medicaid. The program provides comprehensive coverage through Medicaid, including dental and mental health coverage, in return for a premium. Apply at your local Human Service Zone office.

## Children and Family Coverage

Coverage is available to children younger than 21, pregnant women, and adult caretakers of deprived children. Most receive full coverage; however, some with higher income may be required to pay for a portion of their care. Apply at your local Human Service Zone office.

## Children's Hospice Services Waiver

The Children's Hospice Waiver provides support to families so they can care for their children (from birth through age 21) in their homes as long as possible, avoiding lengthy stays and delaying or avoiding institutional care. The child must have a diagnosis and not be expected to live longer than one year. The program also allows families to access treatments that focus on curative and comfort care for their children.

Phone: 701-328-4630

## Children with Medically Fragile Needs Medicaid Waiver

This Medicaid Waiver is designed to assist qualifying medically fragile children between ages three and 18 years. The child must be living at home, be Medicaid eligible, be able to meet Level of Care criteria for a nursing home, and meet criteria based on the Level of Need.

Phone: 701-328-4630

## Home and Community-Based Services Waiver

Alternative services are provided for individuals with disabilities who are at least 18 years of age and individuals older than 65 who are eligible for the Medicaid Program and have medical needs that would qualify them to enter a nursing facility. The waiver allows North Dakota to pay for services needed for these individuals to remain in their own homes or community settings. Recipients may be required to pay for a portion of their care based on income. Apply at your local Human Service Zone office.

## Medicaid Expansion Provides Coverage

Coverage is available to individuals under age 65 with household income up to 138 percent of the Federal Poverty Level (FPL). Individuals eligible for Medicare or Supplemental Security Income (SSI) are not eligible for coverage under Medicaid Expansion. Visit [nd.gov/dhs/eligibility](https://nd.gov/dhs/eligibility) for more information.

## Intellectual Disabilities/Developmental Disabilities Waiver

This waiver assists eligible individuals with intellectual disabilities and developmental disabilities to remain living at home and in the community. This serves individuals through their lifespan (both children and adults). Services offered under the waiver include Developmental Disabilities Program Management; Infant Development (for children from birth to age 3); In-Home Supports; Assistance with cost of equipment, supplies, and environmental modifications; and Adult Services such as day services, job coaching, and residential services. Apply by contacting the Developmental Disabilities Unit at one of the regional human service centers found online at [nd.gov/dhs/locations/regionalhsc](https://nd.gov/dhs/locations/regionalhsc).

## Workers with Disabilities Medicaid Coverage

This coverage allows some individuals with disabilities who want to work, or who are already working and want to increase their earnings, to do so without fear of losing their Medicaid coverage. It allows qualifying individuals to buy into Medicaid. The program provides comprehensive coverage through Medicaid, including dental and mental health coverage, in return for a premium. Apply at your local Human Service Zone office.

## Healthy Steps

This is a benefit program for eligible North Dakota children up to age 19 who do not have a source of health care coverage. The program offers comprehensive medical, dental and vision coverage.

Phone: 877-KIDS-NOW or 877-543-7669

## Special Health Services Financial Coverage Program

Helps families pay for medical services for eligible children, youth, and young adults who require specialty care to diagnose and treat their chronic health conditions.

Phone: 800-755-2714 or 701-328-2436

<https://www.health.nd.gov/youth/special-health-services/SHS-Financial-Coverage->

## Health Insurance Marketplace

The Health Insurance Marketplace enables individuals to find quality health coverage. It can help if you or your child(ren) don't have coverage now, or if you have it but want to look at other options. It is designed to provide coverage that meets your needs, fits your budget, as well as options for qualifying for free or low-cost coverage through Medicaid or Healthy Steps/Children's Health Insurance Program (CHIP).

Phone: 800-318-2596

[healthcare.gov](https://healthcare.gov)

[ndcpd.org](https://ndcpd.org)

## Comprehensive Health Association of North Dakota (CHAND)

CHAND provides comprehensive health insurance to residents of North Dakota who have been denied health insurance or are considered high risk.

Phone: 844-363-8457

[chand.org](https://chand.org)



## Student Health Plans

These plans are available for purchase by students who don't have health insurance through a parent's health insurance policy or who have limited coverage due to network service areas. Student plans are sold by an insurer that has contracted with a college to offer coverage to its students. In general, these plans have more limited benefits and more exclusions than traditional health insurance plans. Contact an insurance agent to inquire about student health plans.

[healthcare.gov/young-adults/college-students/](https://healthcare.gov/young-adults/college-students/)

## Vision Coverage

### InfantSEE®

This is a public health program designed to ensure early detection of eye conditions in babies. Member optometrists provide a comprehensive eye and vision assessment for infants within the first year of life regardless of a family's income or access to insurance coverage.

Phone: 888-396-3937  
[infantsee.org](http://infantsee.org)

### New Eyes for the Needy

New prescription eyeglasses are available through a voucher program for children and adults in the U.S. who cannot afford glasses on their own.

Phone: 973-376-4903  
[new-eyes.org](http://new-eyes.org)

### Vision USA

Vision USA provides basic eye health and vision care services free of charge to uninsured, low-income people and their families.

Phone: 701-258-6766  
[www.ndeyecare.com](http://www.ndeyecare.com)

### VSP Sight for Students

VSP is a charity that provides free vision exams and glasses to low-income, uninsured children.

Phone: 888-290-4964  
[sightforstudents.org](http://sightforstudents.org)





## Prescription Coverage

### Prescription Connection

This is a program of the North Dakota Insurance Department that connects kids and families with free and discounted prescription drugs direct from the pharmaceutical manufacturer.

Phone: 888-575-6611 or 701-328-2440  
[rxconnectnd.org](http://rxconnectnd.org)

### ND Prescription Drug Repository Program

The repository collects and distributes donated medications from hospitals, hospices and other facilities so that pharmacies and physicians can dispense them to those who struggle paying for prescriptions regardless of insurance coverage. The medications and supplies are unopened and secure but cannot be resold to patients. Visit [nodakpharmacy.com](http://nodakpharmacy.com) for more information.

### NeedyMeds

NeedyMeds offers a database of medications that can be obtained free or at low cost by uninsured, low-income patients, usually through manufacturer programs.

Phone: 800-503-6897  
[needymeds.org](http://needymeds.org)

### Partnership for Prescription Assistance

A single point of access is available to more than 475 public and private patient assistance programs. It is funded by pharmaceutical companies.

Phone: 888-477-2669  
<https://medicineassistancetool.org/>

### RX Assist

RX Assist provides consumer information, resources, news and a directory of patient assistance programs that offer affordable or free medications.

Email: [info@rxassist.org](mailto:info@rxassist.org)  
[rxassist.org](http://rxassist.org)

## Dental Coverage

Safety Net Dental Clinics are programs that usually see patients who do not have other access to dental care. The patients typically are covered by Medicaid or the clinic offers sliding fee schedules or reduced fees.

### Bridging the Dental Gap

This is a nonprofit community dental clinic serving low-income and uninsured individuals in the Bismarck-Mandan area.

Phone: 701-221-0518  
[dentalgap.org](http://dentalgap.org)

### Family Healthcare Center Dental Clinic

This is a federally qualified community health center serving low-income and uninsured individuals within the Fargo/Red River Valley Region.

Phone: 701-271-3344  
[famhealthcare.org](http://famhealthcare.org)

### Northland Community Health Center Dental Clinic

This clinic is part of a federally qualified community health center serving low-income, uninsured, and insured individuals of all ages in central North Dakota.

Phone: 701-255-4242  
[northlandchc.org](http://northlandchc.org)

### Red River Valley Dental Access Project

This project serves low-income, uninsured, and Medicaid-eligible individuals who have urgent dental pain and do not have access to a dentist in Fargo-Moorhead.

Phone: 218-790-7790  
[rrdentalaccess.com](http://rrdentalaccess.com)

### Valley Community Health Center Dental Clinic

This is a federally qualified health center that serves low-income, uninsured, and insured individuals of all ages in the Northern Red River Valley.

Phone: 701-757-2100  
[valleychc.org](http://valleychc.org)

### North Dakota Donated Dental Services

This is a network of volunteer dentists who provide dental care to the state's most vulnerable people: disabled, elderly, or medically compromised individuals who cannot afford necessary treatment nor get public aid.

Phone: 866-201-5906  
[dentallifeline.org/north-dakota](http://dentallifeline.org/north-dakota)



### Jerene's Wish

Jerene's Wish is a program that provides orthodontic treatment at minimal costs to eligible children. For more information, contact Warford Orthodontics.

Phone: 701-255-1311

E-mail: [info@warfordorthodontics.com](mailto:info@warfordorthodontics.com)  
[jereneswish.com](http://jereneswish.com)

### Smiles Change Lives

This program promotes and provides access to essential orthodontic treatment for children from low-income families.

Phone: 888-900-3554

[smileschangelives.org](http://smileschangelives.org)

### The Ronald McDonald Care Mobile

This is a mobile dental clinic on wheels that delivers urgently needed dental care to underserved children from birth through age 21 in their own neighborhoods in the western half of North Dakota. The Ronald McDonald Care Mobile treats children who do not have a regular dentist and who have not seen a dentist within the past two years.

Phone: 701-258-8551

[rmhcbismarck.org/caremobile](http://rmhcbismarck.org/caremobile)



## Health Care Programs

### Shriners Hospitals for Children

Shriners Hospitals for Children provides care for children (age 17 and younger) with orthopedic problems and burns. Evaluation clinics are offered throughout North Dakota.

Phone: 800-237-5055  
[shrinershospitalsforchildren.org](http://shrinershospitalsforchildren.org)

### Community Health Centers (CHC)

CHC's serve all patients regardless of their ability to pay for services. CHCs are located in Beulah, Bismarck, Bowbells, Center, Fargo, Grafton, Grand Forks, Hazen, Killdeer, Larimore, McClusky, Minot, Northwood, Rolette, Rolla, Turtle Lake, and West Fargo.

Phone: 701-221-9824

### North Dakota Association for the Disabled (NDAD)

NDAD may provide help with financial assistance for individuals with disabilities.

Phone: 800-532-6323  
[ndad.org](http://ndad.org)

### United Health Care Children's Foundation

This foundation supports the concept of facilitating access to health-related services that have the potential to significantly enhance either the clinical condition or the quality of life of the child and that are not fully covered by an available commercial health benefit plan. The Foundation provides financial assistance toward the family's share of the cost of medical services.

Phone: 855-698-4223  
[uhccf.org](http://uhccf.org)

### Indian Health Service (IHS)

IHS provides health services to American Indians and Alaskan Natives who belong to federally recognized tribes. The IHS administers health services through IHS facilities, through tribally-operated facilities and by contracting for health services. Visit [ihs.gov](http://ihs.gov) for more information.

*Service Organizations such as the Elks, Kiwanis, Sertoma, Lions and Quota may offer assistance with medical-related expenses. Check the local phone book for contact numbers.*

This is not an all-inclusive list of health care coverage options.

# Military Resources

## Medical

Tricare  
Phone: 877-988-9378  
[tricare.mil](http://tricare.mil)

## Exceptional Family Member Program

The Air Force's Exceptional Family Member Program (EFMP) is designed to provide support to military family members with special needs. EFMP is comprised of three components which work together to support military members and their families.

**Minot Air Force Base**  
Phone: 701-723-5527

**Grand Forks Air Force Base**  
Phone: 701-747-5591



## Military OneSource

Military OneSource offers policy and programmatic information, helpful resources, products, articles and tips on numerous topics related to military life. Confidential services are available 24 hours a day by telephone and online. In addition to the website support, Military OneSource offers a confidential call center and online support for consultations on a number of issues such as spouse education and career opportunities, issues specific to families with a member with special needs, health coaching, financial support, and resources.

Phone: 800-342-9647  
[militaryonesource.mil](http://militaryonesource.mil)

# Statewide Tribal Programs

## Fort Berthold Indian Reservation - Three Affiliated Tribes

[mhanation.com](http://mhanation.com)

- Elbowoods Memorial Health..... 701-627-4750
- Community Health Representative
  - .....New Town..... 701-627-4340
  - .....Mandaree ..... 701-421-4188
  - .....Parshall..... 701-898-8532
  - .....Twin Buttes..... 701-898-1273
  - .....White Shield ..... 701-743-4178

## Standing Rock Indian Reservation

[standingrock.org](http://standingrock.org)

- Public Health Service Hospital..... 701-854-3831
- Community Health Representative
  - .....Fort Yates..... 701-854-3856
  - .....Cannonball ..... 701-854-9926
- Tribal Health..... 701-854-7206
- Early Childhood Tracking..... 701-854-3678

## Fort Totten Indian Reservation - Spirit Lake Nation

[spiritlakenation.com](http://spiritlakenation.com)

- Spirit Lake Health Center..... 701-766-1600
- Tribal Health..... 701-766-4236
- Community Health Representative ..... 701-766-4236
- Early Childhood Tracking..... 701-766-1248

## Trenton Indian Service Area

[mytisa.org](http://mytisa.org)

- Trenton Community Clinic ..... 701-774-0461
- Community Health Representative Coordinator..... 701-774-0303
- Tribal Health..... 701-774-0461

## Turtle Mountain Indian Reservation

[tmchippewa.com](http://tmchippewa.com)

- Quentin Burdick Health Facility..... 701-477-6111 or 701-477-8429
- Community Health Representative ..... 701-477-5696
- Tribal Health..... 701-477-6120

# Websites

## Condition-Specific Websites

**Abbott Ross**

[abbviepaf.org](http://abbviepaf.org)

**Baby's First Test**

[babysfirsttest.org](http://babysfirsttest.org)

**Cambrooke Foods**

[cambrooke.com](http://cambrooke.com)

**Centers for Disease Control and Prevention**

[cdc.gov/newbornscreening](http://cdc.gov/newbornscreening)

**Genetic Alliance**

[geneticalliance.org](http://geneticalliance.org)

**Mayo Clinic**

[mayoclinic.org/diseases-conditions/metabolic-syndrome/symptoms-causes/syc-20351916](http://mayoclinic.org/diseases-conditions/metabolic-syndrome/symptoms-causes/syc-20351916)

**Mead Johnson**

[meadjohnson.com](http://meadjohnson.com)

**National Coordinating Center for the Regional Genetic and Newborn Screening Service Collaborative**

[nccrcg.org](http://nccrcg.org)

**National Information Center for Metabolic Diseases**

[climb.org.uk](http://climb.org.uk)

**National Newborn Screening and Global Resource Center**

[genes-r-us.uthscsa.edu](http://genes-r-us.uthscsa.edu)

**Needy Meds**

[needymeds.org](http://needymeds.org)

**Nutricia**

[http://www.medicalfood.com/?\\_ga=2.252391177.162338250.1622723671-1817217120.1605020520](http://www.medicalfood.com/?_ga=2.252391177.162338250.1622723671-1817217120.1605020520)

**Save Babies Through Screening Foundation**

[savebabies.org](http://savebabies.org)

## Additional Websites for Families of Children with Special Health Care Needs

**American Academy of Pediatrics**  
[aap.org](http://aap.org)

**Bright Futures**  
[brightfutures.org](http://brightfutures.org)

**CDC Parent Information**  
[cdc.gov/parents](http://cdc.gov/parents)

**Dr. Greene's House Calls**  
[drgreene.com](http://drgreene.com)

**Early Intervention**  
[nd.gov/dhs/services/disabilities/earlyintervention](http://nd.gov/dhs/services/disabilities/earlyintervention)

**Family Village**  
[thevillagefamily.org](http://thevillagefamily.org)

**Gillette Children's Specialty Healthcare**  
[gillettechildrens.org](http://gillettechildrens.org)

**Got Transition**  
[gottransition.org](http://gottransition.org)

**Healthy Children**  
[healthychildren.org](http://healthychildren.org)

**Institute for Child Health Policy (IHP)**  
[ichp.ufl.edu](http://ichp.ufl.edu)

**Mayo Health Clinic**  
[mayoclinic.org](http://mayoclinic.org)

**Medical Home Portal**  
[medicalhomeportal.org](http://medicalhomeportal.org)

**National Center for Medical Home Implementation**  
[medicalhomeinfo.aap.org](http://medicalhomeinfo.aap.org)

**National Organization for Rare Disorders (NORD)**  
[rarediseases.org](http://rarediseases.org)

**ParentsPlace**  
[parentsplace.jfcs.org](http://parentsplace.jfcs.org)

**Social Security Administration**  
[ssa.gov](http://ssa.gov)

**Starlight/Starbright Children's Foundation**  
[starlight.org](http://starlight.org)

**University of Minnesota Masonic Children's Hospital**  
[mhealth.org/childrens](http://mhealth.org/childrens)



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701-328-2436 or 800-755-2714

Fax: 701-328-1645

E-mail: [dohschsadm@nd.gov](mailto:dohschsadm@nd.gov)

<https://www.health.nd.gov/Youth/special-health-services>

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