

This booklet is intended for both professionals working with families who have a child with special needs and for families/parents/caregivers who are raising a child with special needs. They are but one person of a team who may be working with the child.

This booklet is a resource guide. There are links to websites along with phone numbers and a brief description of what the organization offers. It is our hope that this directory will give you or the families you are working with the tools needed.

# **Emergency Contact Numbers**

**Any Emergency** 911

**Children's Protective Services** 

24 Hours: 1-855-333-7233

Adult Protective Services Statewide: 1-866-654-3219 or Santa Fe: 505-476-4912

**New Mexico Peer-to-Peer Warmline** 

TEXT 1-855-466-7100

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# Resource Guide for Children and Youth with Special Health Care Needs

New Mexico specific resources that target health care needs, financial support, legal aid, parental support, school plans, and recreational opportunities for families and children and youth with special health care needs.





## **General Resources**

# Carrie Tingley Hospital (CTH)

The Carrie Tingley Hospital is a specialized hospital in Albuquerque that caters to children born with birth defects. The hospital offers a variety of multi-disciplinary clinics. Children ages 0 through 21 years are eligible for services at the hospital.

More information can be found online at: https://hsc.unm.edu/health/locations/carrie-tingley-hospital.html

# Children's Medical Services (CMS)

Children's Medical Services is a program under the New Mexico Department of Health-Public Health Division. CMS social workers assist clients to coordinate health, medical and other community resources as they develop and meet child and family goals. Families participate as partners in decision-making regarding their children's medical care and other services. CMS sponsors community-based clinics throughout the state.

It is recommended that as soon as a parent receives a birth defect diagnosis, they contact CMS for referral to services by calling: 1-877-890-4692 or by going online nmhealth.org/about/phd/fhb/cms

# UNMH Center for Development and Disability (CDD) Information Network

The CDD offers over 50 different services including an Autism Spectrum Evaluation Clinic and a Neurocognitive Assessment Clinic (FASD).

Contact the Information Network to be directed to the appropriate resource at 505-272-8549 or go online to www.cdd.unm.edu/infonet

#### Share New Mexico

Share New Mexico is an online, state-wide comprehensive resource directory. This directory helps to find needed resources (such as behavioral and physical health care resources) in a

adolescents.

More information can be found online at www.neuropsychnewmexico.com/ or by calling 505-404-9395.

## Sandia Neuropsychology

An adolescent neuropsychological evaluation assists in better understanding your child's functioning in areas such as memory, attention, perception, coordination, language, and personality. This information will help you and your child's teacher, therapists, and physician provide treatments and interventions for your child that will meet his or her unique needs. Adolescent neuropsychological evaluations are appropriate for ages 15 and up.

More information can be found by calling 505-270-4242 or by going online http://sandianeuropsychology.com/

### • Presbyterian Child and Adolescent Behavioral Health

The child and adolescent behavioral health specialists provide evaluations, amongst other services, to provide for you and your family.

More information can be obtained by calling 505-291-5300 or by going online to https://www.phs.org/doctors-services/services-centers/behavioral-health/behavioral-health/Pages/child-adolescent-kaseman-ct.aspx

- Pediatric Specialist Team
- Pediatric Dentist
- Adult Primary Care Physician
- Adult Specialist Team
- Adult Dentist
- Women's Health Physician

You can check Sharenm.org for help with finding new doctors or dentists as needed.

# Behavioral Health and Addiction Treatment Services Locator

If any behavioral health or addiction treatment services are needed, you can find a facility by calling 1-800-662-4357 or going online to <a href="https://www.findtreatment.samhsa.gov/">www.findtreatment.samhsa.gov/</a>

#### State of New Mexico Behavioral Health Services

This organization provides an online service directory for all programs and services in New Mexico that offer behavioral health information.

More information can be found by calling 1-855-662-7474 or by going online http://newmexico.networkofcare.org/mh/

# UNMH Neuropsychology

UNMH Neuropsychology center provides comprehensive outpatient and inpatient neuropsychological evaluation and consultation services for children (3yrs. +), adolescents and adults. The goal is to provide personalized evaluations in a timely manner to affect positive outcomes for patients and their families.

More information can be obtained by calling 505-272-8833 or by going online hsc.unm.edu/health/patient-care/neuropsychology/

# Neuropsychological Services of New Mexico

Neuropsychological Services of New Mexico provides learning and behavioral evaluations for children (3yrs. +) and

certain area quickly and easily.

More information can be found online at https://sharenm.org/

#### Care Coordination

Care Coordination Services can be obtained through your medical insurance company. This service assists with getting insurance authorizations for services, along with finding a provider as well. The best number to call is the Customer Service Number on your insurance card.

# New Mexico Technology Assistance Program (NMTAP)

NMTAP offers free services to New Mexicans with disabilities to help them get the assistive technology (AT) services they need. NMTAP provides financial loans to obtain AT and training on how to use AT.

More information can be found online at www.tap.gcd.state.nm.us/

#### NM Medical Home Portal

The Medical Home Portal is a good resource for health professionals and families of children and youth with special health care needs.

More information can be found online:

https://nm.medicalhomeportal.org/clinical-practice/building-a-medical-home/children-and-youth-with-special-health-care-needs

# Miracle Flights

Miracle Flights provides individuals and families free medical flights to distant, specialized care and valuable second opinions. Free commercial airline tickets are provided to those who are seeking second opinions, treatment and follow-up care at medical facilities across the U.S., as many times as needed. Miracle Flights does require a physician referral, application, and is based on household income.

For more information, call 800-359-1711 or go online: miracleflights.org

## **Financial Resources**

## United Healthcare Children's Foundation (UHCF)

UHCF is an organization that aims to improve the lives of children by helping families gain access to the care they need through medical grants.

To check your eligibility for a grant or to learn more, call 1-855-698-4223 or go online to www.uhccf.org/

#### Medicaid/CHIP

If parents are unable to afford health insurance, they may qualify for Medicaid or CHIP. These programs are offered and funded through the state of New Mexico.

Apply for Medicaid and CHIP online:

http://www.hsd.state.nm.us/LookingForAssistance/apply-forbenefits.aspx or by Phone: 1-800-318-2596

# Supplemental Security Income (SSI)

SSI is a program that provides financial aid in the form of monthly payments. To be qualified for this program, the recipient must be an adult or child who has both a disability and financial need. Please check the Social Security Blue Book for children to assure that the child has a qualifying diagnosis (for example mild spina bifida may not qualify). Financial need is defined as a limited income and resources.

You can learn more about SSI or apply by going online: www.ssa.gov/ssi secure.ssa.gov or by calling: 1-800-772-1213

# Social Security Disability Insurance (SSDI)

This program is for adults between the ages of 18 and 65 years who are now disabled and unable to work. Eligibility requires that they have worked for a certain amount of time and paid Social Security taxes.

For more information go online: www.ssa.gov/disability/ or call:1-800-772-1213 or 202-452-8097

## **Recreational Resources**

## New Mexico Special Olympics

New Mexico Special Olympics is a non-profit organization. They offer year-round sports training and competition in a variety of Olympic-type sports. To be eligible, you must be 8 years or older and have physical or intellectual disabilities.

More information can be found online: https://sonm.org/

# • Disabled Sports USA

Disabled Sports USA is a non-profit organization. They provide opportunities for disabled individuals to develop independence, confidence, and strength through participation in sports.

Additional information: http://www.disabledsportsusa.com

# Adaptive Sports Program New Mexico

The Adaptive Sports Program offers a wide variety of adaptive sports year round to children and adults ages 6 years and older with disabilities. They offer scholarships to families unable to financially afford an event.

Visit www.adaptivesportsprogram.org/ for more information.

# Carrie Tingley Hospital Foundation

The CTH Foundation offers week-long camps dedicated to children and teens with physical disabilities.

For more information, go online

http://www.carrietingleyhospitalfoundation.org/programs/campadventure/or call 505-243-6626

# **Behavioral and Physical Health Care Needs**

Throughout life, your child will require a variety of physicians and specialists. Below are listed general categories for the needed doctors throughout life:

• Pediatric Primary Care Physician

Go online to: https://nmhealth.org/about/ddsd/pgsv/fit/ or call 1-877-696-1472

# • Early Childhood Evaluation Program (ECEP)

The ECEP provides developmental evaluations for children ages 0 to three years who live in New Mexico. This is the first step to getting your child the developmental help that he or she needs.

To learn more about the ECEP, go online to <a href="http://cdd.unm.edu/ecep/index.html">http://cdd.unm.edu/ecep/index.html</a> or call: 505-272-9846

# Individualized Education Program (IEP)

An IEP, or individualized education plan, helps children develop skills at school. An IEP is a legal document that lets the school know what kinds of support will be needed by a child during the school day. The document is created by parents and school personnel. Any child who is enrolled in special education classes will have an IEP.

For more information about an IEP or how to develop an IEP, review the following resource online:

https://www.understood.org/en/school-learning/special-services/504-plan/the-difference-between-ieps-and-504-plans or contact your local school division

#### • 504 Plan

Students in school settings fall under the protection of the Rehabilitation Act of 1973—Section 504. This law protects disabled students from discrimination at school. This covers all school programs and activities in any school that receives federal funding. This plan is only offered to disabled students who are not already part of an IEP.

More information can be found online:

https://www.understood.org/en/school-learning/special-services/504-plan/the-difference-between-ieps-and-504-plans or by contacting your local school division

## • Developmental Disabilities Supports Division (DDSD)

The New Mexico Department of Health DDSD oversees the waiver programs. Due to the financial need in NM, it can take years to get on a waiver.

More information regarding specific programs and services can be found online: https://nmhealth.org/about/ddsd/ or you can call 505-841-5552

#### MI VIA Self-Directed Waiver

Mi Via, which means "my path", "my way" or "my road", is designed to assist individuals with disabilities in managing their own services and supports to live their best lives. This program is a person-centered, community-oriented approach to deliver services and supports that assist eligible children and adults with Intellectual and Developmental Disabilities (IDD) or Medically Fragile conditions to participate as active members of their communities.

For more information or to apply, go to: https://nmhealth.org/about/ddsd/pgsv/sdw/

# Centennial Care Waiver (CCW) for Community Benefit (Old Colts or D and E Waiver)

The community based waiver is for families with a child that has significant needs and do not qualify for Medicaid due to making too much. This waiver is intended to fill the gap between Medicaid restrictions and family income.

To apply call Aging and Long Term Services and complete an assessment:

TTY: 505-476-4937 or 1-800-432-2080, option #2

# **Developmental Disabilities Waiver**

The developmental disabilities waiver program provides services and supports to assist eligible children and adults with intellectual and developmental disabilities in participating as active members in their communities. To qualify, the child needs to show significant delay in 3 areas of life skills. Services include case management, living care arrangements, community supports and employment, and professional services.

More information can be found online: https://nmhealth.org/about/ddsd/pgsv/ddw/

# Medically Fragile Waiver

The medically fragile waiver program is specific to individuals who have been determined to have both a medically fragile condition and a developmental disability, with the goal being that they may continue to live in their homes. This program provides case management, private duty nursing, home health aids, comprehensive therapy, counseling, and specialized medical equipment.

More information can be found by going online: https://nmhealth.org/about/ddsd/ pgsv/mfw/ or calling: 1-877-696-1472 or by emailing: Santafemailbox.ddsd@state.nm.us

# Women, Infants, and Children (WIC)

WIC, a program under the New Mexico Department of Health-Public Health Division, is a food program for women, infants, and children. WIC may help provide certain nutritious foods or needs to qualifying individuals and families. To qualify, the mother must be pregnant, breastfeeding, or have a child under 5 years of age.

You can learn more about WIC or contact your local WIC coordinator online: http://archive.nmwic.org/

or call 1-866-867-3124

## First Hand Foundation

First Hand is dedicated to impacting the health of children, their families and communities through reactive and preventative initiatives. To fulfill that mission, they provide funding for

## Pull Together

Pull Together is an organization that enlists parents, families, community members, and young people in the fight to make sure their children are safe, cared for, and ready to succeed.

To find resources that are available in your county go online: https://pulltogether.org/ or by calling: 1-800-691-9067

#### Got Transition

Got Transition is a resource for individuals and their families who are transitioning from adolescence into adulthood. This organization provides resources regarding how to transition and transfer health care from childhood into adulthood. This organization acts as a resource for adolescents and young adults to achieve independence.

More information can be found online: www.gottransition.org or by calling: 202-223-1500 or by emailing: info@gottransition.org

#### Lexiam Heart Foundation

Lexiam Heart Foundation provides support to children and families in New Mexico affected by congenital heart defects. Support comes in the form of parent-to-parent support groups and financial support.

More information can be found online: http://lexiamheartfoundation.org/

# **Developmental and Educational Resources**

# • Early Intervention (EI)

The New Mexico Department of Health-Developmental Disabilities Support Division's Family Infant Toddler (FIT) program provides a statewide system of early intervention in accordance with the Individuals with Disabilities Education Act (IDEA) Part C. Early intervention services are provided through a network of early intervention provider agencies across New Mexico.

general advocacy efforts; and training activities to increase awareness of disability rights.

More information can be found online: http://www.drnm.org/ or by calling: 1-800-432-4682

#### My Child Without Limits

My Child Without Limits offers support and resources for parents, caregivers, and experts. On their website, you can find descriptive information on issues such as guardianship and power of attorney. Additionally, they host an online community for parents to communicate and support each other.

More information can be found online: http://www.mychildwithoutlimits.org/

# **Family Support Resources**

## • Parents Reaching Out (PRO)

Parents Reaching Out is a non-profit organization that works with parents, caregivers, educators, and other professionals to promote healthy, positive and caring experiences for families and children.

More information can be found online:

http://parentsreachingout.org/

or calling: 505-247-0192 or 1-800-524-5176

# Education for Parents of Indian Children with Special Needs (EPICS)

EPICS is a community parent resource center that focuses on providing free learning opportunities to families who have Native American children with disabilities or developmental delays in New Mexico. They additionally provide ongoing advocacy support and parent-to-parent connections.

More information and resources can be found online:

http://www.epicsnm.org/

or calling:505-767-6630 or 1-888-499-2070

individual children with health-related needs when insurance and other financial resources have been exhausted.

More information can be found online at www.firsthandfoundation.org/ or calling 816-201-1569

# **Legal Resources**

## Native American Rights Fund (NARF)

NARF is a non-profit organization that provides legal assistance to American Indian individuals nationwide who might go without adequate representation otherwise.

More information can be found online at https://www.narf.org/ or by calling 303-447-8760

## Southwest Indian Law Clinic (SILC)

The SILC provides student attorneys to represent American Indian clients in state, federal, and tribal courts and in governmental agency hearings.

More information can be found by calling 505-277-5265 or going online at http://lawschool.unm.edu/indian/indian-clinic.html

#### Native American Disabilities Law Center

Provides advocacy, referral information, and educational resources to all American Indian individuals with a disability living anywhere in the Four Corners area.

More information can be found online at: https://www.nativedisabilitylaw.org/ or by calling 1-800-862-7271

# Guardianship

Guardianship is a legal arrangement in which a person or persons are legally authorized to make decisions for another adult person. This role includes decisions about basic needs such as food, clothing, shelter, medical care, and financial management. Depending on the abilities of your child, this option should be explored as your child nears adulthood.

More information about guardianship can be found online at www.nmguardianshipassoc.org or https://nm.medicalhomeportal.org/services/provider/19048.

You can also contact the help line at 1-800-980-1165 statewide or 505-217-1660 in Albuquerque.

# Pegasus

Pegasus provides legal service for children. This is a private, non-profit agency that serves New Mexico's vulnerable children and youth.

If a parent is considering a guardianship for their child, it is recommended that they contact Pegasus at 505-244-1101 for legal advice.

#### Law Access New Mexico

Law access New Mexico makes accessing legal advice easy for low-income New Mexicans. This organization can provide recommendations on whether a parent can be their own lawyer or can make a referral if necessary.

For more information, call 505-998-4529 in Albuquerque or 1-800-340-9771 statewide. To learn more, go online to www.lawaccess.org

# UNM Legal Alliance for Children

UNM Law School and Medical School collaborated to address the non-medical needs of children in Bernalillo County. The law school provides students help with matters ranging from tenant disputes to immigration matters.

Call 505-277-5265 for more information.

# Establishing Financial Accounts

Establishing a financial resource for disabled individuals can be a difficult task. There are two general options available: STABLE

Accounts and Special Needs Trusts. Depending on individual circumstances, one account may be better than the other.

#### STABLE Accounts

The ABLE Act was signed into Law in New Mexico the end of 2016. This law allows persons with disabilities to establish tax-free savings accounts without the threat of losing their eligibility for public assistance.

More information can be found online: https://ablenewmexico.com/stable-account/

#### Special Needs Trust

One way of providing for a child with special needs after the death of a parent is through a Special Needs Trust (SNT). A SNT has several requirements. It is recommended that you obtain legal aid when setting up a trust.

For more information, go online: https://nm.medicalhomeportal.org/living-with-child/legalissues/special-needs-trusts or contact an attorney

#### The Arc of New Mexico

The Arc of New Mexico promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes. They provide resources such as links for financial planning, guardianship recommendations, and they actively participate in public policy.

More information can be found online: https://www.arcnm.org/ or by calling:505-767-6630 or 1-888-499-2070

# • Disability Rights New Mexico (DRNM)

DRNM is a non-profit organization that promotes, protects, and expands the rights of persons with disabilities. DRNM fulfills their mission by providing the following services: information and referral regarding legal rights; individual case advocacy services;