



This booklet is intended for families/parents/caregivers raising a child with a diagnosis of spina bifida.

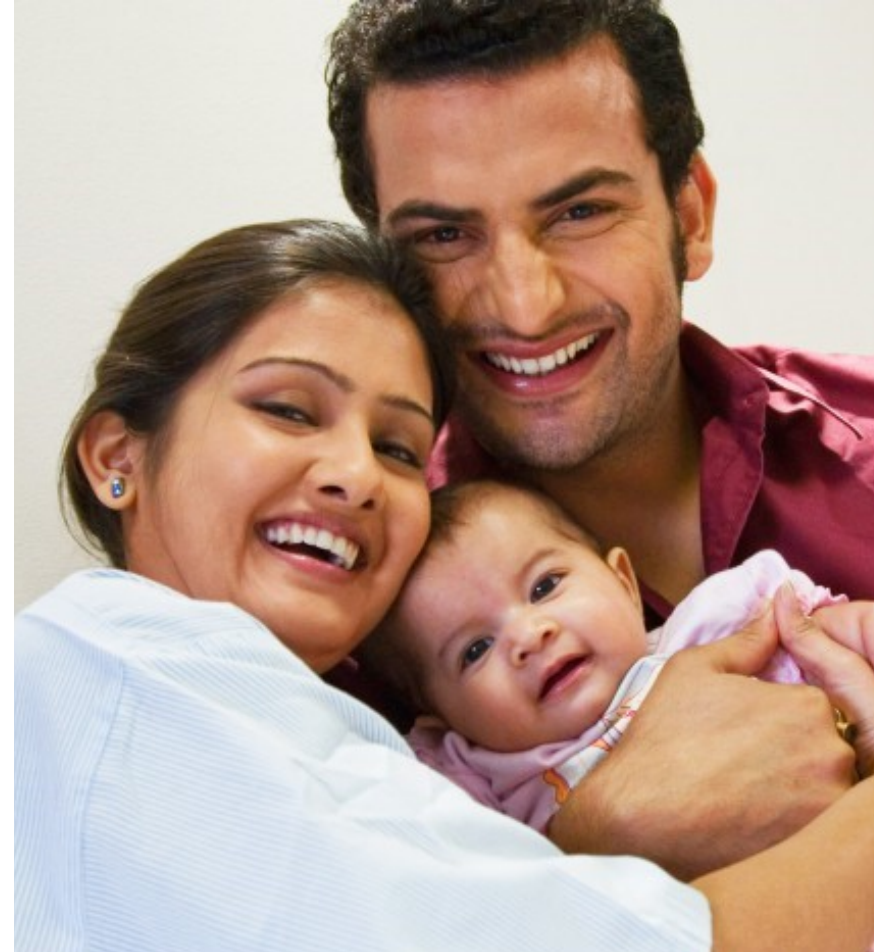
The booklet is a resource guide. There are links to websites along with phone numbers. Your child's team of specialists will also be an invaluable resource as they can direct you along the way.

Spina bifida means 'split spine'. This is not an illness but a lifelong condition. Spina bifida happens when a baby is in the womb and the spinal column does not close all the way. Every day, about 8 babies born in the United States have spina bifida or a similar birth defect of the brain and spine.

Children with spina bifida can lead full lives. Most do well in school, and many play in sports. Because of today's medicine, about 90% of babies born with spina bifida now live to be adults, about 80% have normal intelligence and about 75% play sports and do other fun activities.

It is our hope that this directory will give you the tools necessary to assist you and your child.

Spina Bifida Resource Guide for Families



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 specific for children with spina bifida. Children ages 0 through 21 years are eligible for services. More information can be found online at: <https://hsc.unm.edu/health/locations/carrie-tingley-hospital.html> or by calling 505-272-5200

- **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 <https://nmhealth.org/about/phd/fhb/cms>

- **Spina Bifida Association**

The Spina Bifida Association offers a variety of resources for parents of children with spina bifida. They also offer various support options through social media. More information can be found online: <http://spinabifidaassociation.org/>

- **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/ or by calling 505-841-4464

- **Share New Mexico**

Share New Mexico is an online, state-wide comprehensive re-

with disabilities. They offer scholarships to families unable to financially afford an event. Visit www.adaptivesportsprogram.org/ for more information.

- **Carrie Tingley Hospital Foundations**

The CTH Foundation offers week-long camps dedicated to children and teens with physical disabilities. For more information, go online to <http://www.carrietingleyhospitalfoundation.org/programs/camp-adventure/> or call 505-243-6626

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
- 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.

Emergency Contact Numbers

Any Emergency

911

Children’s Protective Services

24 Hours: 1-855-333-7233

Adult Protective Services

Statewide: 1-866-654-3219

Santa Fe: 505-476-4912

New Mexico Peer-to-Peer Warmline

TEXT 1-855-466-7100

online: <http://www.dnm.org/> or by calling: 1-800-432-4682

- **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 by phone: 202-223-1500 or by email: info@gottransition.org

- **Pull Together**

Pull Together is an organization that enlists the entire community the fight to make sure that children are safe, cared for, and ready to succeed. To find resources that are available in your county go online: <https://pulltogether.org/> or call: 1-800-691-9067

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 can be found at <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

source directory. This directory helps to find needed resources (such as behavioral and physical health care resources) in a 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.

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/

- **Developmental Disabilities Supports Division (DDSD)**

The New Mexico Department of Health DDSD oversees the waiver programs. Due to the 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 calling 505-841-5552

- **Medically Fragile Waiver**

The medically fragile waiver offers services to help eligible individuals continue to live in their homes. Eligibility requires that an individual have both a medically fragile condition and a developmental disability. This program provides case management, private duty nursing, home health aids, comprehensive therapy, counseling, and specialized medical equipment. More information can be

found online: <https://nmhealth.org/about/ddsd/pgsv/mfw/>
by phone: 1-877-696-1472 or by email: Santafemail-box.ddsd@state.nm.us

- **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. Mi Via uses a community setting to assist eligible children and adults with developmental disabilities so that they can 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**

The community based waiver is for families with a child who has significant needs and who 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 uses a community setting to assist eligible children and adults with developmental disabilities in being active members of their communities. 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/>

- **Medicaid/CHIP**

If parents are unable to afford health insurance, you 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-for-benefits.aspx> or by phone: 1-800-318-2596

- **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. PRO promotes healthy, positive and caring experiences for families and children. More information can be found online: <http://parentsreachingout.org/> or by calling: 505-247-0192 or 1-800-524-5176

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

EPICS is a New Mexican parent resource center that provides free learning opportunities to families who have Native American children with disabilities or developmental delays. They provide ongoing advocacy support and parent-to-parent connections. More information and resources can be found online: <http://www.epicsnm.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; general advocacy efforts; and training activities to increase awareness of disability rights. More information can be found

dress 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](tel: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://ablenuewmexico.com/stable-account/>

- **Special Needs Trust**

One way of providing for your child with special needs after your death 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/legal-issues/special-needs-trusts> or contact [an attorney](#)

- **The Arc New Mexico**

The Arc New Mexico promotes and protects the human rights of people with intellectual and developmental disabilities. They actively support the full inclusion and participation of people with disabilities in the community throughout their lifetimes. The Arc provides resources for financial planning and guardianship recommendations. More information can be found online:

<https://www.arcnm.org/> or by calling: [505-767-6630](tel:505-767-6630) or [1-888-499-2070](tel:1-888-499-2070)

- **Supplemental Security Income (SSI)**

SSI is a program that provides financial aid in the form of monthly payments. To be qualified for this program, you must be an adult or child who has a disability and financial need. 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/apps6zi3820/main.html or by calling: [1-800-772-1213](tel: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](tel:1-800-772-1213) or [202-452-8097](tel:202-452-8097)

- **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](tel:1-866-867-3124)

Developmental and Educational Resources

- **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

<http://cdd.unm.edu/ecep/index.html> or call [505-272-9846](tel:505-272-9846) or [contact your local school division.](#)

- **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](#)

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](tel: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](tel:505-277-5265) or going online at <http://lawschool.unm.edu/indian/indian-clinic.html>

- **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](tel:1-800-980-1165) statewide or [505-217-1660](tel:505-217-1660) in Albuquerque.

- **NM Medical Home Portal**

The Medical Home Portal is a good resource to help parents understand guardianship and why it may be necessary. More information can be found online:

<https://nm.medicalhomeportal.org/living-with-child/legal-issues/guardianship>

- **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](tel:505-244-1101) for legal advice.

- **Law Access New Mexico**

Law access New Mexico makes legal advice accessible for all New Mexicans. This organization offers recommendations can make a referral to a law office if necessary. They can be contacted at [505-998-4529](tel:505-998-4529) in Albuquerque or [1-800-340-9771](tel: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 ad-