



# Texas Parent to Parent NICU National & Statewide Resource Information

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## **Texas Parent to Parent**

(512) 458-8600  
(866) 896-6001  
[www.txp2p.org](http://www.txp2p.org)

A statewide non-profit developed for parents by parents: provides parent to parent matches, emotional support and information for parents of babies who spent time in a Neonatal Intensive Care Unit.

### **Mission:**

Texas Parent to Parent supports children with disabilities, chronic illness, and other special healthcare needs by empowering their parents to be advocates for them through peer support, resource referral and public awareness.

## **Services**

### **2-1-1 Texas**

2-1-1  
(877) 541-7905  
(877) 833-4211 (TTY)  
<https://www.211texas.org>

2-1-1 Texas provides information on and access to Medicaid, Food Stamps, Temporary Assistance for Needy Families (TANF), Children's Health Insurance, nursing home care and other services. When callers dial 2-1-1, they are connected to area information centers in their region. 2-1-1 is a partnership with the Texas Health and Human Services Commission and Area Information Centers statewide. The goal is to be a "one stop" comprehensive, confidential information and community resource.

### **Texas Early Hearing Detection and Intervention (TEHDI)**

(800) 252-8023  
<http://www.dshs.state.tx.us/tehdi/Audiology-Services-Home.aspx>

The TEHDI program is designed to identify newborns with potential hearing loss, do further testing to define the degree and type of hearing loss, fit them with hearing aids if appropriate, and enroll them in intervention services prior to six months of age

### **Texas Department of State Health Services, Women, Infants and Children Program (WIC)**

(800) 942-3678  
<http://www.dshs.state.tx.us/wichd/>

The Special Supplemental Nutrition Program for Women, Infant and Children, known as WIC, is a nutrition program that helps pregnant women, new mothers, and young children eat well, learn about nutrition, and stay healthy. WIC provides nutrition education and counseling, nutritious foods, breastfeeding information and help accessing health care to low-income women, infants, and children.



## **Services, continued**

WIC's *Breastmilk-Every Ounce Counts* -Website with a link to identify community resources to support breastfeeding including WIC clinics and Milk banks. Under the "Every Ounce Counts Campaign" link you can create your own birth announcement; there is also a link to "Sing to Me" – A Lullaby Album which includes songs by Texas musicians focused on mothers and babies and it includes a downloadable file of all the songs.

<http://www.breastmilkcounts.com/resources.html>

## **Texas WIC Breast Pump Program**

(800) 942-3678

[www.texaswic.org](http://www.texaswic.org)

All WIC moms with a premature infant or who are separated from their infant due to medical reasons are eligible to receive (on loan) a hospital grade pump. Women noted enrolled in WIC may qualify based on household income. Contact a local WIC office for more information.

## **Department of Assistive and Rehabilitative Services (DARS)**

### **ECI (Early Childhood Intervention)**

(800) 628-5115

(866) 581-9328 TTY

[www.dars.state.tx.us/ecis/](http://www.dars.state.tx.us/ecis/)

Services for children, birth to 3-years-old, who have a developmental delay or disability. Services are provided in the home and community. ECI uses a family-centered team approach to develop a plan for the family to help the child grow and learn. Team members come from a variety of professions including Early Intervention Specialists, Nurses, Registered Dietitians, Therapists and Social Workers. **There is no cost to the family for an evaluation.** Services are provided on a sliding scale but no family will be denied services due to an inability to pay. ECI produces a range of materials helpful to families, including a Resource Guide describing programs, services and resources for families.

### **Division for Blind Services (DARS)**

#### **Formerly Texas Commission for the Blind**

(800) 628-5115

(866) 581-9328 TTY

[www.dars.state.tx.us/dbis/](http://www.dars.state.tx.us/dbis/)

The Blind Children's Vocational and Discovery Program provides information and support to help families who have a child that is blind or visually impaired. A Blind Children's Program Specialist – an expert in providing services to children with visual impairments – works with each child and family to create a Family Service Plan. Their focus is on restoring vision and reducing dependency.



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## **Services, continued**

### **Office of Deaf and Hard of Hearing Services**

**Formerly Texas Commission for the Deaf**

**(800) 628-5115**

**(866) 581-9328 TTY**

[www.dars.state.tx.us/dhhs/index.shtml](http://www.dars.state.tx.us/dhhs/index.shtml)

Information and referral for persons that are deaf/hard of hearing, their family members and their service providers. Provides financial assistance for hearing aids, assists with local interpreter services and sponsor summer camps for children and youth that are deaf/hard of hearing. Hearing Loss Resource Specialists (HLRS) provide services to persons with hearing loss.

### **Department of Aging and Disability Services (DADS)**

**Formerly MHMR (Mental Health & Mental Retardation)**

**(800) 458-9858**

[www.dads.state.tx.us](http://www.dads.state.tx.us)

Provides some services and financial programs like respite money, In-Home and Family Support program and Medicaid waiver programs

## **Internet Support and Information Related to Premature Babies**

### **La Leche League**

<http://www.llli.org/>

(800) 525-3243

Their Mission is to help mothers worldwide to breastfeed through mother-to-mother support, encouragement, information, and education, and to promote a better understanding of breastfeeding as an important element in the healthy development of the baby and mother.

Their website includes links to helpful resources, includes a forum for breastfeeding a preemie and downloadable podcasts on a variety of topics.

### **National Organization of Mothers of Twins Clubs**

<http://www.nomotc.org/>

The National Organization of Mothers of Twins Clubs, Inc. is a non-profit organization dedicated to supporting families of multiple birth children through education, research, and networking.



## **Internet Resources, continued**

### **March of Dimes-NICU**

<http://www.marchofdimes.com/baby/inthenicu.html>

Information for parents of babies in the NICU. Includes a reference guide with NICU related terms, common tests, typical questions and answers, a list of NICU staff and their roles, tips for surviving the NICU experience, how to advocate for your baby and information about how to make the transition from the hospital to home. This web site also includes a mechanism for submitting questions.

March of Dimes hosts an on-line community featuring, sharing your story, discussion of topics related to the NICU and a mechanism for blogging about your experience.

<http://www.shareyourstory.org/webx/Share%20Home/>

### **Inspire-Premie Support Community**

<http://www.inspire.com/groups/premie/discussions>

Inspire connects patients, families, friends, caregivers, and health professionals for health and wellness support. The Premie Support Community is one of their online discussion and support networks.

### **Premie Voices**

<http://premievoices.com/Default.aspx>

Information to help families navigate the journey of prematurity. Website contains fifteen documents focusing on topics of interest to families of premature babies, for example, 5 Reasons for Hospitalization, Premie Glossary, Milestones, Special Needs, Keeping Baby Healthy. Most materials are available in English and Spanish. The material is developed by a division of MedImmune, LLC focused on advocacy for premies. The website contains information on national and legislative issues impacting premies, as well as many helpful resources targeted for families.

### **Premies Today**

<http://www.premiestoday.org/index.php>

A national premies support network, is a non-profit organization founded by parents of premies. Resources include monthly on-line chats and listservs that allow families to connect based on their child's age, English and Spanish newsletter and resource information (including downloads on feeding and sensory development).



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## **Internet Resources, continued**

### **PreemieCare**

<http://www.preemiecare.org/index.htm>

PreemieCare is a division of MOST (Mothers of Supertwins), Inc. a non-profit parenting organization that provides information, education, support and additional resources for families of multiples. PreemieCare has a special focus on RSV awareness and prevention. Issues such as breastfeeding preemies, parenting in the NICU, early intervention are also addressed by PreemieCare, as are networking opportunities for preemie support groups.

### **Preemie Prints**

[www.preemieprints.org](http://www.preemieprints.org)

Preemie Prints is a Texas 501(c)3 non profit organization dedicated to sharing hope with families experiencing the difficulties of life in a neonatal intensive care unit with a premature or sick baby through information, photography, gift bags, support, and prayer. Preemie Prints offers face to face, online and group meetings in the Brazos Valley and Fort Bend County area, Houston, Waco and Temple.

### **American Academy of Pediatrics/ About HealthyChildren.org**

<http://www.healthychildren.org/english/ages-stages/Pages/default.aspx>

HealthyChildren.org is a parenting website backed by the American Academy of Pediatrics. It provides general information related to child health and guidance on parenting issues. Covered topics include ages and stages information (including a section on preemies that addresses topics about life in the NICU and making the transition home), immunizations and a wide variety of health, nutrition, wellness and current pediatric health issues. Users are able to register and customize receipt of information according to age and interest. There is an "Ask a Pediatrician" tool that allows users to browse a database of current questions and submit questions to be answered.

### **Zero to Three**

ZERO TO THREE is a national nonprofit organization that informs, trains and supports professionals, policy leaders and parents in their efforts to improve the lives of infants and toddlers. Includes resources for families related to solving parenting issues and guidance on nurturing a child's growth and learning. The focus is on general parenting issues and topics and is an excellent resource on the early development of a child.

<http://www.zerotothree.org/>



## **Insurance**

### **SSI (Supplemental Security Income)**

(800) 772-1213

[www.ssa.gov/](http://www.ssa.gov/)

Social Security provides SSI disability benefits (including Medicaid) to certain infants born with a low birth weight whether or not they are premature. A child weighing less than 1200 grams (about 2 pounds, 10 ounces) at birth can qualify for SSI based on low birth weight. A child weighing between 1200 and 2000 grams (about 4 pounds, 6 ounces) at birth and considered small for his or her gestational age also may qualify.

[http://ssa-custhelp.ssa.gov/app/answers/detail/a\\_id/368](http://ssa-custhelp.ssa.gov/app/answers/detail/a_id/368)

### **Family and Medical Leave Act (FMLA)**

<http://www.dol.gov/dol/topic/benefits-leave/fmla.htm>

The federal Family and Medical Leave Act (FMLA) provides certain employees with up to 12 weeks of unpaid, job-protected leave per year. **It also requires that their group health benefits be maintained during the leave.** FMLA is designed to help employees balance their work and family responsibilities by allowing them to take reasonable unpaid leave for certain family and medical reasons. It also seeks to accommodate the legitimate interests of employers and promote equal employment opportunity for men and women.

FMLA applies to all public agencies, all public and private elementary and secondary schools, and companies with 50 or more employees. These employers must provide an eligible employee with up to 12 weeks of unpaid leave each year for any of the following reasons for the birth and care of the newborn child of an employee; for placement with the employee of a child for adoption or foster care; to care for an immediate family member (spouse, child, or parent) with a serious health condition; or to take medical leave when the employee is unable to work because of a serious health condition.

### **The Texas Health Insurance Pool**

(888) 398-3927

Risk pool for those persons who are uninsurable.

[www.txhealthpool.org](http://www.txhealthpool.org)

### **CHIP- Children's Health Insurance Program**

(800) 647-6558

A national program designed for families who earn too much money to qualify for Medicaid, yet cannot afford to buy private insurance.

<http://www.chipmedicaid.com/>

### **CHIP – Perinatal Children's Health Insurance Program**

(877) 543-7669

The Children's Health Insurance Program (CHIP) perinatal coverage provides prenatal care for the unborn children of low-income women who do not qualify for Medicaid. CHIP perinatal coverage starts before the child is born and lasts 12 months from the date the unborn child is enrolled.

<http://www.chipmedicaid.org/en/CHIP-Perinatal>



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## **Insurance, continued**

### **HIPP –Health Insurance Premium Payment Reimbursement Program**

**(800) 440-0493**

This is a Medicaid program that pays for the cost of premiums, coinsurance, deductibles, and other cost sharing. The program reimburses the policy holder due to private health insurance payroll deductions for Medicaid eligible persons when it is determined to be cost effective.

[www.gethipptexas.com](http://www.gethipptexas.com)

### **Medicaid**

**(800) 252-8263**

Low-income families may qualify for this program by income or in extreme situations when medical expenses exceed income. The website includes information on other Medicaid programs like Kidney Health Care, Medical Transportation and others

[www.hhsc.state.tx.us/medicaid/contacts.html](http://www.hhsc.state.tx.us/medicaid/contacts.html)

### **Medicaid-Texas Health Steps**

**(877) 847-8377**

This program makes sure that complete health services are available to children, teens and young adults up to the age of 21, who are enrolled in Medicaid. This includes medical and dental check-ups, eye and hearing screenings, lab tests and shots, eye glasses and hearing aids, prescriptions, and case management for children with special health care needs.

<http://www.dshs.state.tx.us/thsteps/>

### **CSHCN - Children with Special Health Care Needs**

**(800) 252-8023**

The Children with Special Health Care Needs (CSHCN) is made up of several programs that provides services to children with extraordinary medical needs, disabilities, and chronic health conditions. The CSHCN health care benefits program pays for medical care, family support services, and related services not covered by Medicaid, CHIP, private insurance, or other “third party payor.”

[www.dshs.state.tx.us/cshcn](http://www.dshs.state.tx.us/cshcn)

### **Pre-Existing Condition Insurance Plan (PCIP)**

**(866) 717-5826**

Federal Program – Providing health coverage for eligible children and adults with pre-existing conditions.

[www.pcip.gov](http://www.pcip.gov)



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## **Insurance, continued**

### **Medicaid Buy-In for Children**

Medicaid Buy-In for Children can help pay medical bills for children with disabilities. This program helps families who need health insurance, but make too much money to get traditional Medicaid. Families “buy in” to Medicaid by making a monthly payment (premium).

**1-877-541-7905**

<http://www.hhsc.state.tx.us/Help/HealthCare/Children/MBIC.html>

### **Shriners Hospitals for Children**

**800-237-5055**

Children up to the age of 18 with orthopedic conditions, burns, spinal cord injuries and cleft lip and palate are eligible for admission and receive all care in a family-centered environment at no charge regardless of financial need.

[www.shrinershq.org/Hospitals](http://www.shrinershq.org/Hospitals)

## **Transportation**

### **Medical Transportation Program (through TX Dept. of Transportation)**

**(877) 633-8747**

Provides eligible Medicaid clients, under 21 with non-emergency transportation services to Medicaid covered medical and dental care.

[www.hhsc.state.tx.us/QuickAnswers/GetRide\\_FAQs.shtml](http://www.hhsc.state.tx.us/QuickAnswers/GetRide_FAQs.shtml)

## **Other Services:**

### **The Arc of Texas**

**(800) 252-9729**

[www.thearcoftexas.org](http://www.thearcoftexas.org)

The Arc of Texas is affiliated with the Arc of the United States and has 48 chapters in Texas working to provide additional community supports and services to families with children or individuals with intellectual and developmental disabilities throughout the State.

## **Advocacy**

### **Disability Rights Texas**

**(800)-252-9108**

A Federally funded agency (every state has one) that advocates for people with disabilities. They can only help people whose issues are one of their current priorities although their website has lots of useful information and they can send you information. Sometimes a call can get you an answer to a specific question. State office located in Austin, with branches around the state.

[www.disabilityrightstx.org](http://www.disabilityrightstx.org)





## **Medicaid Waiver Programs**

**These programs are based on child's income (not the parents) in order for them to qualify for Medicaid and receive additional services that will allow a child to remain in the community as opposed to a nursing home or institution. The programs provide funding for a personal attendant, respite, therapies, adaptive aids, home and vehicle modifications, etc.**

**The below listed programs are all found on the following website:**

**[www.dads.state.tx.us](http://www.dads.state.tx.us)**

### **MDCP (Medically Dependent Children's Program)**

**(877) 438-5658**

This program provides a variety of services to support families caring for children who are medically dependent and to keep the children in their communities.

**[www.dads.state.tx.us/services/faqs-fact/mdcp.html](http://www.dads.state.tx.us/services/faqs-fact/mdcp.html)**

### **In-Home and Family Support Services**

**(877) 438-5658**

This program provides direct grant benefits to adults and children with disabilities to purchase services to let them live in the community.

(Waiting list)

**[www.dads.state.tx.us/services/faqs-fact/ifs.html](http://www.dads.state.tx.us/services/faqs-fact/ifs.html)**

### **CLASS (Community Living Assistance Support Services)**

**(877) 438-5658**

This program provides home- and community-based services to people with related conditions as a cost-effective alternative to placement in an intermediate care facility. (A related condition is a disability, other than mental retardation, that originated before age 22 and that affects the ability to function in daily life.) (Waiting list)

**[www.dads.state.tx.us/services/faqs-fact/class.html](http://www.dads.state.tx.us/services/faqs-fact/class.html)**

### **Community Based Alternatives (CBA)**

**(800) 458-9858**

This program provides home- and community-based services to people who are elderly and to adults with disabilities as a cost-effective alternative to living in a nursing home. (Waiting list)

**[www.dads.state.tx.us/services/faqs-fact/cba.html](http://www.dads.state.tx.us/services/faqs-fact/cba.html)**



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## **Medicaid Waiver's continued**

### **MRLA (Mental Retardation Local Authority) or HCS (Home and Community Services)**

**(800) 458-9858**

MHMR Medicaid waiver programs  
(Waiting list)

[www.dads.state.tx.us/services/faqs-fact/hcs.html](http://www.dads.state.tx.us/services/faqs-fact/hcs.html)

### **Texas Home Living Program (TxHmL)**

**(800) 458-9858**

Provides selected essential services and supports to people with intellectual and developmental disabilities who live in their family homes or their own homes.

[www.dads.state.tx.us/services/faqs-fact/txhtml.html](http://www.dads.state.tx.us/services/faqs-fact/txhtml.html)

**You may need to contact your local Texas Department of Aging and Disability Services to find out what specific Medicaid Waiver Programs are available in your area.**

## **National Resources**

### **NICHCY (National Dissemination Center for Children with Disabilities)**

**(800) 695-0285**

Disability library and information on related services; produces state resource sheet.

<http://nichcy.org>

### **Exceptional Parent Magazine**

**(877) 372-7368**

Monthly magazine for parents and professionals; National website includes resources for parent to parent programs; information and referral centers, disability library, services, products and much more.

[www.eparent.com](http://www.eparent.com)

### **Family Village**

[www.familyvillage.wisc.edu](http://www.familyvillage.wisc.edu)

A global community that integrates information, resources, disabilities library and communication opportunities on the internet

### **NORD (National Organization for Rare Disorders)**

**(800) 999-6673**

Information and referrals on rare disorders

[www.rarediseases.org](http://www.rarediseases.org)



## **National Resources, continued**

### **MUMS (Mothers United for Moral Support)**

(920) 336-5333 National parent to parent network which provides information and  
(877) 336-5333 emotional support to parents whose child has a rare disorder.  
(toll free for parents only)  
[www.netnet.net/mums/](http://www.netnet.net/mums/)

### **NIH (National Institute of Health)**

(301) 496-4000 Stephen Groft at the office of rare diseases provides information  
[www.nih.gov](http://www.nih.gov) on which hospitals and physicians are doing research or clinical trials on any  
disease.

### **NAMI (National Association for Mental Illness)**

(800) 950-6264 Provides information and training programs for caregivers of  
[www.nami.org](http://www.nami.org) individuals with mental health issues or brain disorders.

### **National Fathers Network**

[www.fathersnetwork.org/](http://www.fathersnetwork.org/) Provides training and emotional support for fathers of children  
with special health care needs and developmental disabilities.

**Please visit our website Resource Directory for other resources that may be available in your area. We appreciate your notifying us of any changes that may need to be made to this list or the website. [www.txp2p.org](http://www.txp2p.org)**

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