Austin Area Resource Guide For Children With Special Needs
Austin Area Resource Guide for Children with Special Needs

Copyright © 2010 Complex Chronic Illness Parent Advisory Group (CChIPAG) Steering Committee
Austin, Texas

All Rights Reserved
No part of this book may be reproduced or utilized in any form or by any means, electronic or mechanical, including photocopying, recording or by any information storage and retrieval system without permission in writing

Printed by McCarthy Print, Inc.
Austin, TX
www.mccarthyprint.com

The Austin Area Resource Guide is intended to provide parents with a start in locating resources and services for children with disabilities. It is not intended as a comprehensive listing of information and services in the Austin area and surrounding communities. A listing in this Guide does not imply a recommendation, endorsement, promise, or guarantee of any kind by the publishers or authors. The information in this Guide is not intended to be medical advice. All listings are current at the time of publication but are subject to change thereafter.

Portions of this guide, including template, gratefully used with permission from Resource Guide for Parents of Children with Disabilities: Houston and Surrounding Communities © 2008 by Elaine Hime. Any changes made were to reflect local contact information and updates in services provided.

Cover Art by Alex R. Age 11
Back art by Matt K. Age 7

For more information about this guide please contact: CChIPAG Coordinator at CChIPAG@seton.org
<table>
<thead>
<tr>
<th>TABLE OF CONTENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
</tr>
<tr>
<td>Information Resources</td>
</tr>
<tr>
<td>National</td>
</tr>
<tr>
<td>State</td>
</tr>
<tr>
<td>Parent Support</td>
</tr>
<tr>
<td>Financial Assistance</td>
</tr>
<tr>
<td>Private Health Insurance</td>
</tr>
<tr>
<td>Social Security Programs</td>
</tr>
<tr>
<td>Medicaid Programs</td>
</tr>
<tr>
<td>Medicaid Waiver Programs</td>
</tr>
<tr>
<td>Other Government Programs</td>
</tr>
<tr>
<td>Estate and Financial Planning</td>
</tr>
<tr>
<td>Transportation</td>
</tr>
<tr>
<td>Advocacy</td>
</tr>
<tr>
<td>Early Childhood Intervention</td>
</tr>
<tr>
<td>Education</td>
</tr>
<tr>
<td>Information</td>
</tr>
<tr>
<td>Advocacy</td>
</tr>
<tr>
<td>Schools</td>
</tr>
<tr>
<td>Therapy</td>
</tr>
<tr>
<td>Hippotherapy</td>
</tr>
<tr>
<td>Aquatic Therapy</td>
</tr>
<tr>
<td>Recreation and Respite</td>
</tr>
<tr>
<td>Nursing Agencies</td>
</tr>
<tr>
<td>Durable and Home Medical Equipment</td>
</tr>
<tr>
<td>Religious and Spiritual Resources</td>
</tr>
<tr>
<td>Palliative Care</td>
</tr>
<tr>
<td>End-of-Life Planning and Support</td>
</tr>
<tr>
<td>Information</td>
</tr>
<tr>
<td>Hospices</td>
</tr>
<tr>
<td>Bereavement Support</td>
</tr>
<tr>
<td>Index</td>
</tr>
</tbody>
</table>
Introduction

The Complex Chronic Illness Parent Advisory Group, (CChIPAG) was created in 2008, by a group of concerned parents. They hold in common a profound commitment to the holistic care of their children and to the on-going development of the Palliative Care Program at Dell Children’s Medical Center of Central Texas, at Austin. Each shares their unique experiences while bringing thoughtful and constructive ideas to the table. With a focus on streamlining care within the community, this working group has ongoing projects in parent support, transition services, respite programs, and care-coordination.

CChIPAG produced the *Austin Area Resource Guide for Children with Special Needs* to provide a broad overview of the myriad of products and services available in our community. We have created this guide to empower parents to make better informed decisions about the care of their children. For some families the resources included in this guide may serve as a first step in the path taken with your child. For others it may present new ideas and new options. Wherever your family is on its journey, we hope that this guide will help you along the way.

~the Parent Members of the CChIPAG Steering Committee
INFORMATION RESOURCES

Autism Speaks
A national informational and advocacy website that includes sections on science, awareness, and family services, including services for Texas.

Download the First 100 Days Kit under the “Be Informed” section of the website. Created specifically for families to make the best possible use of the 100 days following a diagnosis.
www.autismspeaks.org

Exceptional Parent Magazine
Published 11 times a year for parents of children with disabilities.

Customer Service
P.O. Box 2078
Marion, OH 43306-2178
877.372.7368
www.eparent.com

Family Voices
A national grassroots network of families and friends, which advocates for health care services that are family-centered, community-based, comprehensive, coordinated, and culturally competent for all children and youth with special health care needs.

2340 Alamo SE, Suite 102
Albuquerque, NM 87106
888.835.5669
www.familyvoices.org
The Fathers Network
Supports fathers and families of children with special healthcare needs and developmental disabilities.

Greg Schell, Program Director
Washington State Fathers Network, Kindering Center
16120 NE Eighth Street
Bellevue, WA 98008-3937
425.653.4286
www.fathersnetwork.org

IAN Community
An interactive autism community that links the autism community to researchers. Includes research studies, state statistics, and newsletter.
www.iancommunity.org

Institute for Patient- and Family-Centered Care
The Institute of Patient- and Family-Centered Care, a non-profit organization, provides essential leadership to advance the understanding and practice of patient- and family-centered care. The Institute serves as a central resource for both family members and members of the health care field.

7900 Wisconsin Avenue, Suite 405
Bethesda, MD 20814
301.652.0281
www.ipfcc.org

Mothers United for Moral Support Inc. (MUMS) National Parent to Parent Network
Parent-to-parent network organization for parents or care providers of children with disabilities. Provides a national networking system that matches parents with other parents of children with similar conditions. Publishes a quarterly newsletter.

c/o Julie Gordon
150 Custer Court
Green Bay, WI 54301
920.336.5333 or 877.336.5333 (parents only)
www.netnet.net/mums
The National Center of Medical Home Initiatives for Children with Special Needs
The goal of this program is to ensure that children with special needs have a medical home where health care services are accessible, family-centered, continuous, comprehensive, coordinated, compassionate and culturally-competent. Through the National Center (AAP), physicians, parents, administrators and other health professionals have access to educational, resource and advocacy materials, guidelines for care, evaluation tools, and technical assistance.

141 Northwest Point Blvd.
Elk Grove Village, IL 60007
847.434.4000
www.medicalhomeinfo.org

National Dissemination Center for Children with Disabilities (NICHCY)
Offers a free package of information about national and state resources, a publication list, and various booklets.

P.O. Box 1492
Washington, D.C. 20013-1492
800.695.0285
www.nichcy.org

National Organization for Rare Disorders (NORD)
Provides current information on rare and orphan diseases, including newsletters, research information, and networking for members.

55 Kenosia Avenue
PO Box 1968
Danbury, CT 06813-1968
203.744.0100 or 800.999.6673 (voicemail only)
www.rarediseases.org

Sibling Support Project
Provides publications, training, and technical assistance to help organize peer-support and education programs for siblings of people with disabilities. Conducts workshops throughout the United States for families and service providers.

6512 23rd Avenue NW, Suite 213
Seattle, WA 98117
206.297.6368
www.siblingsupport.org
United Cerebral Palsy Association
Provides general information and an information packet about cerebral palsy.
1660 L Street NW, Suite 700
Washington, D.C. 20036
800.U.S.A.5UCP (5827)
www.ucp.org

United Leukodystrophy Foundation (ULF)
Provides information, education, and resources for those diagnosed with a leukodystrophy.
2304 Highland Drive
Sycamore, Illinois USA 60178
800.728.5483
www.ulf.org
http://www.ucp.org/

United Mitochondrial Disease Foundation (UMDF)
Provides families with information on diagnosis and cure of mitochondrial diseases. This includes family support, research updates and a resource guide.
8085 Saltsburg Road, Suite 201
Pittsburgh, PA 15239
412.793.8077
www.umdf.org

State

Deaf Blind Multi-Handicapped Association of Texas (DBMAT)
DBMAT’s mission is to promote and improve the quality of life for all Texans who are deaf, blind, and multi-handicapped and blind, multi-handicapped.
4230 LBJ Freeway
LB #31, #340
Dallas, TX 75244
Austin Area Contact: 512.462.1422
www.dbmat-tx.org

EveryChild, Inc.
The mission of EveryChild is to ensure the development of family-based alternatives for
children with disabilities residing in institutional settings or at risk of out-of-home placement and to ensure the availability of family supports needed so children have the opportunity to grow up in a loving, nurturing and enduring relationship within a family.

8400 North Mopac, Suite 201
Austin, TX 78759
877.742.8844 or 512.342.8847
www.everychildtexas.org

Texas Autism Advocacy
An interactive information, resource, and support list for parents and professionals who serve individuals with Autism Spectrum Disorders.
www.TexasAutismAdvocacy.org

Texas Center for Disability Studies (TxCDS), University of Texas at Austin
The mission of TxCDS is to serve as a catalyst so that people with developmental and other disabilities are fully included in all levels of their communities and in control of their lives. TxCDS consists of an inter-disciplinary team of professionals at the university level, persons with disabilities from state, regional and local communities, statewide services providers and advocacy organizations.

JJ Pickle Research Campus
10100 Burnet Road
The Commons Center, Bldg 137, Suite 1.154
Austin, TX 78758
512.232.0761 or 800.828.7839
tcds.edb.utexas.edu

Texas Council for Developmental Disabilities (TxCDD)
The mission of TxCDD is to create change so that all people with disabilities are fully included in their communities and exercise control over their own lives.

6201 Oltorf, Suite 600
Austin, TX 78741
800.262.0334 or 512.437.5432
www.txdcc.state.tx.us
Texas Parent to Parent (TxP2P)
TxP2P empowers families to be advocates for their children with disabilities, chronic illnesses, and other special needs through peer support, resource referral and public awareness. Publishes a regional online resource guide.

3710 Cedar Street, Box 12
Austin, TX 78705
866.896.6001 or 512.458.8600
www.txp2p.org

Texas Technology Access Project (TTAP)
The TTAP provides information, conducts training and technical assistance and works with policy makers to support children and adults with disabilities in their efforts to acquire and use technology as a routine part of day-to-day living.

University of Texas at Austin
4030-2 West Braker Lane, Suite 220
Austin, TX
800.828.7839 (answered by TxCDS)
techaccess.edb.utexas.edu

PARENT SUPPORT

Candlelighters Childhood Cancer Program
Candlelighters is a program within Any Baby Can. They serve children with cancer and their families by providing services such as advocacy, counseling, support groups, case management, and family events throughout the year.

Any Baby Can
1121 E. 7th
Austin, TX 78702
512.454.3743, 800.672.0238
www.abcaus.org/candlelighters

Caregiver Support Group for Parents and Family Members of Children with Complex Chronic Conditions
Initiated by CChIPAG, this group meets to discuss ongoing issues, including emotional support, for families with children who have children with complex chronic conditions. Professionally facilitated by Jane Dryden Louis,
Complex Chronic Illness Parent Advisory Group (CChIPAG)
A working group of parents focused on enhancing existing supports and identifying where support is needed. Through education projects, and community collaboration CChIPAG works to meet the needs of the pediatric complex chronic illness community.
CChIPAG supports the Caregiver Support Group for Parents and Family Members of Children with Complex Chronic Conditions.

Contact: CChIPAG Coordinator, Kendra Koch
512.324.9999 x86690
CCHIPAG@seton.org
http://dellchildrens.net/CChIPAG

Down Syndrome Association of Central Texas
A comprehensive association providing education, advocacy, activities, and resources. Visit DSACT’s website for current support group information and locations.

Epilepsy Family Support Group
Support and ongoing education for families and children affected by epilepsy and other seizure disorders. Meets monthly at Dell Children’s Medical Center. Dinner and Childcare provided. See website for calendar.

888.606.5353 (Epilepsy Foundation)
Local Contact: Terri Carriker (SFC Neurology Parent Representative)
E-mail: tdcarriker@austin.rr.com
www.epilepsyfoundation.org/local/efcst

Family Support Cooperative
The Family and School Support Team for AISD special education hosts the Family Support Cooperative. The Co-Op meetings are open to anyone in central Texas and provide free childcare and pizza, as well as support groups and information sessions on a wide range of topics. Several team members speak Spanish and they provide all materials in Spanish and English.

Contact Rosemary Alexander: 512.414.0955
Alternate: 512.414.2049 or 512.414.0959

Special Needs Neighborhood
Website created by two mothers with special needs children, acts as a user-generated forum for parents to find local resources.
www.specialneedsneighborhood.com

Texas Child Study Center
A collaboration between Dell Children’s Medical Center and the College of Education of UT to provide evidence-based treatment for children and adolescents with emotional, behavioral, and developmental disabilities. The evaluations and interventional programs are disease-specific for those with emotional and cognitive diagnoses. They provide ongoing assessment and treatment with core mental health services.

1600 W. 38th Street, Suite 212
Austin, TX 78731
512.324.3315
www.dellchildrens.net
(Select “Services and Programs” then “Texas Child Study Center”)

U.R. Our Hope
Assisting those with undiagnosed or rare conditions at any age and any stage. They provide both support and advocacy to families and their children. Education and Support meetings available. See website for dates and times.

512.288.2812
www.urourhope.org
FINANCIAL ASSISTANCE

Financial aid comes in two basic forms: private health insurance and government assistance. Your child may qualify for a number of programs offered by federal, state or local government agencies. Many government programs have waiting lists that are many years long. It is very important to sign up as early as possible.

Private Health Insurance

Your employer can provide information about your insurance coverage, or you can call your insurance provider directly. Ask about limits or “caps” on the amount your insurance will pay for the treatment of certain conditions. Some plans have lifetime limits of certain amounts. If your insurance has limits, you can investigate other funding sources such as Early Childhood Intervention Programs (page 24) for therapy and equipment. Use Early Childhood Intervention Programs when you can. Save your insurance to pay for ongoing chronic health problems. In some cases, you can combine private insurance with other financial aid.

Texas Department of Insurance

To order the booklet, call 800.599.7467 or 800.252.3439
www.tdi.state.tx.us

Health Insurance Premium Payment Reimbursement Program
See page 16.
Acronyms for State Agencies

HHSC
Health and Human Services Commission

MHMRA
Mental Health and Mental Retardation Authority

TxDADS
Texas Department of Aging and Disability Services

TxDARS
Texas Department of Assistive and Rehabilitative Services (previous legacy agency)

TxDSHS
Texas Department of State Health Services

Social Security Programs

Supplemental Security Income (SSI)
SSI provides monthly assistance for children with disabilities. The amount paid is based on your family income, the number of people in your family, and the severity of the disability. Your child can receive up to approximately $550 a month. Even if your child receives as little as $1 of SSI, the child also qualifies for Medicaid.

800.772.1213
www.ssa.gov/disability

SSI for Low-Weight and Premature Infants
Many very low birth-weight babies and premature infants can be eligible for SSI benefits and Medicaid from the date of “Intent to File” (also referred to as the “protected filing date”) to the date of discharge from the hospital. The people answering the SSI 800 number may not be familiar with this program, so rely on your local Social Security Administration office for help. During your first call, state your “intent to file” for benefits. This will give you the earliest possible eligibility date.
Medicaid Programs

Medicaid, HHSC
Title XIX of the Social Security Act provides certain medical benefits for families with low income or people with disabilities. To qualify for Medicaid in Texas, your child must meet at least one of the following criteria:

• Receive SSI from Social Security

• Qualify for benefits through the Temporary Assistance for Needy Families (TANF) based on low family income

• Qualify under the Medically Needy Program (page 16) or

• Receive assistance from one of the three Medicaid Waiver Programs: MDCP (page 18), CLASS (page 18), or HCS (page 19).

These three programs are one type of Medicaid waiver program that waives the family-income requirement and counts the child’s income to qualify for Medicaid.
800.252.8263 or 512.424.6500

STAR Program (Medicaid Managed Care)
Mothers and children in Travis and surrounding counties who qualify for Temporary Assistance to Needy Families (TANF) receive their Medicaid benefits through the Medicaid Managed Care program known as STAR. The STAR Program offers the choice of selecting one of the STAR health maintenance organizations (HMOs). From these choices, the member is required to select a primary care provider (PCP) who coordinates the member’s health care. The STAR program includes children with disabilities who are not on SSI.

Amerigroup 800.600.4441
Superior 800.783.5386
STAR+PLUS (Medicaid Managed Care)
Children with disabilities in Travis County and surrounding counties who receive SSI may participate in the STAR+PLUS HMOs or select traditional, fee-for-service Medicaid. The HCS, MDCP, and CLASS programs do not participate in STAR+PLUS. Children with disabilities who have primary insurance through a private insurance provider and secondary Medicaid coverage may choose not to participate in STAR+PLUS.

Amerigroup 800.600.4441
Evercare 888.887.9003

Texas Health Steps, TxDSHS Children and Pregnant Women
If your child qualifies for Medicaid, the child also qualifies for Texas Health Steps, which provides free medical screening exams, dental services, and case management.

For help finding a provider call: 877.847.8377 (877 THSTEPS)
or Region 7 (serving Travis County and most of Central Texas): 254.778.6744 ext.2321

Comprehensive Care Program (CCP)
The Comprehensive Care Program is an extension of Texas Health Steps for children under age 21. Services not normally covered by Medicaid can be covered if your medical provider obtains prior authorization or can document on the claim form that a medical necessity requires the services or equipment. Examples of some covered services include unlimited prescriptions for children under age 21, RN or LVN services, medically necessary supplies, such as equipment for tube feeding, diapers for older children, and therapy services. Note: Medicaid and CSHCN (see page 14) pay for diapers and wipes if they are considered “medically necessary” for children over age 4 and sometimes for ages 2-4 depending on the type and severity of disability. Contact a local medical equipment supplier (see page 39) regarding ordering “incontinent supplies”. A letter of “medical necessity” will need to be acquired from the physician. In most cases the supplier will contact the physician and then submit paperwork to Medicaid.
Health Insurance Premium Payment Reimbursement Program

Health Insurance Premium Payment Reimbursement Program (HIPP)

HIPP is a Medicaid program that pays the cost of insurance premiums, co-insurance, deductibles and other cost sharing. HIPP will reimburse the health-insurance premiums of payroll deductions for Medicaid-eligible persons, but only when Medicaid determines it would be cost effective. The advantage of this program is that members of your family who are not eligible for Medicaid will be covered under your private health insurance plan. If your Medicaid benefits are provided through the STAR or STAR+PLUS program, you can apply for the HIPP program only if you are a member of the Texas Health Network.

800.440.0493

Medically Needy Program (MNP), HHSC

The Medically Needy Program (MNP) is an option under Texas Medicaid. Families who meet Medicaid assets requirements, but whose income is too high for regular Medicaid, can “spend down” into Medicaid eligibility using the family medical bills. The spend-down amount works much like a deductible amount for a private health insurance policy. A spend-down amount is calculated for each month that you have medical expenses. A case can be set up for the month you apply or for the three months before the application month. You must renew MNP eligibility every 30 days. Note: This program can be complicated. If the case worker is not familiar with MNP, ask for a supervisor.

Children’s Health Insurance Plan, CHIP - HHSC

The Children’s Health Insurance Program (CHIP) is designed for families who earn too much money to qualify for Medicaid health care, yet cannot afford to buy private insurance. Families may pay monthly premiums and co-pays. There is an income limit and an assets test. Note: Also apply for CSHCN Program that will be secondary insurance with CHIP. See page 17.

800.647.6558 or 877.543.7669
Children with Special Health Care Needs Division (CSHCN), TxDSHS

CSHCN provides health care benefits, family support services, and case management to children in Texas with special health care needs (chronic illness and/or medically-based disabilities). In addition, the family must meet specific income limits (except for case management, any income), assets, and residency requirements. The CSHCN income limits are slightly higher than Medicaid (SSI) and the same as CHIP. CSHCN can be used as secondary insurance with Medicaid, CHIP, and private insurance. There is a waiting list for health care benefits and family support services based on urgent need and severity, plus time spent on the waiting list. Once eligible for services, a child may receive treatment and obtain equipment or supplies through a group of physicians, therapists, and other providers enrolled in the CSHCN service program.

CSHCN will require you to apply and obtain denial letters from Medicaid and the Medically Needy Program (page 16) of TxDADS before CSHCN will pay for services. This process can be complicated, so be persistent and rely on the CSHCN medical social workers for help. If your family’s income is too high to qualify, ask about the “spend-down” program. If your child is on Medicaid, you may still want to apply for CSHCN because CSHCN may pay for a few services Medicaid will not cover. The Insurance Premium Payment Assistance (IPPA) is a program that allows CSHCN to reimburse families for insurance premiums paid to provide health insurance for a CSHCN client. To be eligible for IPPA, a client must have CSHCN eligibility and any type of third party resource. See note under CCP on page 15.

512.458.7355 or 800.252.8023
www.dshs.state.tx.us/cshcn
Medicaid Waiver Programs

Medically Dependent Children Program (MDCP)
This Medicaid waiver program provides qualified children with a variety of services that allow the children to live at home. MDCP provides respite, adaptive aids, and supports to enable eligible children to participate in child care. To qualify, only the child’s income is considered. A physician must agree that your child meets medical necessity criteria for admission to a nursing home. MDCP is limited to a certain number of children on a first-come, first-served basis. Once accepted, your child also qualifies for Medicaid benefits. Note: Long waiting list.

A number of MDCP slots are reserved for children who reside in Texas nursing homes, enabling them to return home with support.

Telephone number for information and to place a name on the waiting/interest list: 877. 438.5658
Community Care Services, TxDADS
www.dads.state.tx.us/providers/mdcp

Note: The MDCP ends when a child reaches age 21. After that the Community Based Alternative (CBA) continues most services, but the change from MDCP to CBA is not automatic. You must apply for CBA separately, but the eligible child will access CBA services directly without being placed on a waiting list. State that the child is reaching 21 and on the MDCP. For more information, call 877.438.3436 (intake line).

Community Living Assistance and Support Services (CLASS)
CLASS provides home and community services such as therapies and personal-attendant care, limited nursing care, job training, daily living skills, adaptive aids, psychological counseling, home medication and respite care for persons with disabilities other than the primary diagnosis of mental retardation. CLASS is funded by Medicaid through a waiver that allows participants to live in the community with a
degree of freedom and choice. Qualification is based on approved needs. Applicants for CLASS services must have demonstrated needs for, and be able to benefit from, habilitation assistance and support services. Once accepted, the child also qualifies for regular Medicaid benefits. Note: Several years-long waiting list.

Telephone number to place a name on the waiting/interest list: 877. 438.5658
Community Care Services, TxDADS
www.dads.state.tx.us/services/class

**Home and Community-Based Services (HCS)**
Mental Retardation Services Dept. (MRSD), TxDADS (under contract to MHMRAs)
www.dads.state.tx.us/providers/hcs

The HCS program is a Medicaid waiver program that provides services to individuals with mental retardation who either live with their families, in their own home, in a foster/companion care setting or in a residence with not more than four individuals who receive services. HSC services include residential assistance, day habilitation, respite, nursing, attendant care, adaptive aids, counseling, therapy, minor home modification, and supported employment. Call for eligibility.

**Travis County**
Austin Travis County Integral Care
512.472.4357

**Williamson County**
Bluebonnet Trails Community MHMR Center
512.255.1720

**Hays County**
Hill Country Community MHMR Center
512.558.2006

**Texas Home Living Waiver (TxHmL)**
Mental Retardation Services Department (MRSD), TxDADS (under contract to MHMRAs)
www.dads.state.tx.us/providers/txhml

The TxHmL program is one type of Medicaid waiver that waives a Medicaid requirement so that a list of services such as respite can be...
delivered by someone other than a licensed practitioner (doctor, etc.), and paid by Medicaid. Therefore, the family’s income must meet eligibility for Medicaid to qualify. The TxHmL program provides essential services and support so that Texans with mental retardation can continue to live with their families or in their homes in the community. TxHmL services are intended to supplement. TxHmL is limited to an annual cost of $10,000 per participant. This is a new program and MHMRAs contacts families from the HCS waiting list.

Travis County
Austin Travis County Integral Care
512.472.4357

Williamson County
Bluebonnet Trails Community MHMR Center
512.255.1720

Hays County
Hill Country Community MHMR Center
512.558.2006

Other Government Programs

Division of Blind Services, TxDARS
The Division of Blind Services provides an array of services to children with visual impairments. The services include eye restoration services, eye medical care, parent counseling, educational and training opportunities, and case management.
800.687.7008 or 512.533.7100

Deaf and Hard of Hearing Services, TxDARS
The mission of DHHS is to eliminate communication barriers and guarantee equal access. DHHS provides communication access, information and referral, and an early-intervention program.
CSD of Texas
877.744.1364 or 512.428.1813

In Home and Family Support (IH&FS), TxDADS
IH&FS provides the funding for yearly grants of up to $2,500 (MHMRA) or $1,200 (CCS-TxDADS) to individuals or their families. The family may receive assistance to access
services related to their child’s disability that maintains or improves their child’s ability to live at home/community. The grant monies can be used for specialized equipment, home modifications, medical services, personnel attendants, training and respite. There are income limits (much higher than Medicaid), and co-pays may apply. The two following departments under DADS have the IH&FS program. Note: Waiting lists.

**IH&FS Mental Retardation Services Department (MRSD), TxDADS**
Under contract to MHMRAs.
Serves children under age 4 who have one area of mental or physical developmental delay, age 4 or older, children and adults with mental retardation, Rett’s, and autism spectrum disorders. If your child after age 4 does not have the above diagnoses, request MRSD transfer your child’s name with original application date to the IH&FS program under DADS Community Care Services. Note: Waiting list. (*This program could be eliminated and combined with IH&FS, CCS-DADS see below.)

Travis County
Austin Travis County Integral Care
512.472.4357

Williamson County
Bluebonnet Trails Community MHMR Center
512.255.1720

Hays County
Hill Country Community MHMR Center
512.558.2006

**IH&FS Community Care Services, TxDADS**
Serves people over age 4 with physical disabilities, with or without developmental delay. Note: Short waiting list.
Hays, Travis and Williamson Counties
512.908.9435

**Primary Home Care (PHC) Community Care Programs**
TxDADS
www.dads.state.tx.us/providers/phc

PHC provides non-skilled, non-technical, medically related personal care, household
tasks, meal preparation, escort, shopping and assistance with self-administered medication. A physician must order the service and a nurse must supervise delivery. There is an income limit, and your child must be Medicaid-eligible. A case manager will assess the needs to determine eligibility and service delivery.

Hays, Travis and Williamson Counties
512.908.9435

Non-educational Funding (Non-ed) Local School District
Non-educational funds are appropriated to school districts to provide non-educational community-based support services to certain students and their families. Funds are available for eligible students with disabilities who would have to be placed in or who would remain in resident facilities primarily for educational reasons without access to non-educational funds. Support services include in-home family support, respite care, attendant care and family dynamic training. Non-ed funds must be discussed outside the ARD process and cannot be used for educational purposes. Contact your special education department chairperson at the district level. Application required.

Education Service Center Region XIII
512.919.5313
www5.esc13.net/noned

ESTATE AND FINANCIAL PLANNING

Trust funds are private arrangements made by the families of children with disabilities. Trust funds may take many different forms. Parent support groups can usually provide information and sources of help in establishing trust funds.

Advocacy, Inc
Provides handouts on estate planning and guardianship.

78000 Shoal Creek #171 E
Austin, TX 78757
512.454.4816 or 1.800.252.9180
www.advocacyinc.org
Arc of the Capital Area
Assists families who qualify with guardianship of a family member with disabilities.

2818 San Gabriel
Austin, TX 78705
512.476.7044
www.arcofthecapitalarea.org/guardianship.php

TRANSPORTATION

Medicaid Transportation
Transportation assistance for medical appointments can be obtained for those who receive Medicaid; mileage reimbursement for Medicaid appointments.
Call 877.633.8747

Metro Access
Capital Metro offers transportation for individuals with physical and mental disabilities with accessible buses, vans, and taxi vouchers.

Information & Reservations 512.478.9647
Administrative Office 512.389.7480
Capital Metro Customer Service 512.474.1200

ADVOCACY

Advocacy, Inc
An organization that works to protect and advance the rights of people with disabilities.

78000 Shoal Creek #171 E
Austin, TX 78757
512.454.4816 or 1.800.252.9108
www.advocacyinc.org

Austin Resource Center for Independent Living (ARCIL)
Transition, information, advocacy, referrals: ARCIL, Inc. of Austin, Texas provides independent living services to persons with disabilities, their families and communities throughout Travis and surrounding counties. ARCIL also provides services throughout Hays, Caldwell, Comal and Blanco counties at ARCIL San Marcos (San Marcos, Texas), and Williamson, Bell, Burnett and Milam counties at ARCIL Round Rock (Round Rock, Texas).
Arc of the Capital Area
Provides a variety of services including case management, parent mentoring, guardianship services, and respite. Visit their website for a full list of programs and services.

2818 San Gabriel
Austin, TX 78705
512.476.7044
www.arcofthecapitalarea.org

The Disability Policy Consortium
A consortium created to advocate for and advance the rights of Texan's with disabilities. DPC's website offers lists of disability specific organizations and legislative issues.

1016 La Posada, Suite 145
Austin, TX 78752
www.dpctexas.org

EARLY CHILDHOOD INTERVENTION (ECI)

ECI programs are free therapy programs provided to children from birth to three years of age. ECI programs are divided by county and then further by Zip Code.

For those in Travis County call the DARS Inquiry Line at 800.628.5115 or go to www.dars.state.tx.us/ecis
See ECI providers below:

Travis County

Any Baby Can Child and Family Resource Center
1121 East 7th Street
Austin, TX 78702
Referral Number: 512.334.4464
www.abcaus.org
Austin Travis County Integral Care
Infant Parent Program
1717 West 10th Street
Austin, TX 78703
Referral Number: 512.472.3142
www.atcmhmr.com

Easter Seals Central Texas
1611 Headway Circle, Bldg. 2
Austin, TX 78754
Referral Number: 512.615.6896
www.centraltx.easterseals.com

Hays County
Hill Country Community MHMR Center
ECI Homespun
1901 Dutton Drive, Ste. D
San Marcos, TX 78666
Referral Number: 888.827.7063
www.hillcountry.org

Williamson and Bastrop Counties
Bluebonnet Trails Community MHMR Center
ECI PRIDE Program
1009 Georgetown St
Round Rock, TX 78664
Referral Number: 866.897.7433
www.bluebonnetmhmr.org

EDUCATION

Wright’s Law
Wright’s Law website has information on special education law (IDEA and No Child Left Behind), advocacy for children with disabilities and a Yellow Pages list of regional resources.
www.wrightslaw.com

Texas Education Agency (TEA)
www.tea.state.tx.us

TEA Parent Special Education Information Line
Special education staff are available to help parents with concerns about their child’s education.
800.252.9668
For Texas Education Law, including the Individuals with Disabilities Education Act (IDEA) Autism Supplement visit: www.tea.state.tx.us/rules/tac/chapter089/ch089aa.html

**Advocacy**

**PATH Project**
The PATH Project provides training, information, and support to parents of children and youth with disabilities from the ages of 0 to 26. They assist parents and provide support in area of special education, educational laws, and service agencies at no cost to parents.

Parent Training and Information Center
1090 Longfellow Drive, Suite B
Beaumont, TX 77706
800.866.4726
www.partnerstx.org

Austin area contact:
Darla Bower
512.642.4226
centxpath@austin.rr.com

**Schools**

**Texas School for the Blind and Visually Impaired**
TSBVI serves as a specialized public school for those who are blind, deafblind, or visually impaired. They offer residential programs as well as short-term and summer programs. Community outreach and parent support also available.

1100 W. 45th St.
Austin, TX 78756
512.454.8631 or 800.872.5273
www.tsbvi.edu

**Texas School for the Deaf**
TSD is a specialized, public-funded school for those who are deaf or hard of hearing. They provide services to infants through high school and offer home-based services through ECI, residential programs, summer programs, and continuing education classes.
Educational Resource Center on Deafness
Offers information, resources, workshops, and interpreter training, among other services.

800.DEAFTSD
www.tsd.state.tx.us/outreach

Statewide Hispanic Liaison for TSD
María Muñiz
877.936.5296

Local School Districts Parent Liaison for Special Education
Parent liaisons offer support in navigating the educational system. They are knowledgeable in community programs and local service agencies and often provide training to parents as well as school staff. Note: if your district is not included call the district's main line and ask for the Special Ed Parent Liaison.

Austin ISD
Rosemary Alexander
512.414.2049
ralexan2@austinisd.org

Eanes ISD
Caroline Nelson
512.732.9000 ext. 20423

Georgetown ISD
Dawn Jennings
512.943.5000 ext 6884
jenningsD@georgetownisd.org

Hays CISD
Nancy Payton
512.268.8250 ext 6990
paytonn@hayscisd.net

Leander ISD
Debi McNiff
512.434.5377
debi.mcniff@leanderisd.org
All therapy groups included take Medicaid or may be paid for through Medicaid Waiver programs, as well as most major insurances. The following agencies offer a variety of services such as physical, occupational, and speech therapies, as well as some specialized therapies. Contact the agencies for more information.

**Austin's Communication Station**  
*clinic-based*  
314 East Highland Mall Blvd, Ste 204  
Austin, TX 78752  
512.610.1190  
www.austinscommunicationstation.com

**Blue Sky Abilities**  
*Home and community-based*  
*Includes specialized therapies*  
P.O. Box 151173  
Austin, TX 78715  
www.blueskyabilities.com

**Capital Area Speech**  
*clinic-based*  
12710 Research Blvd, Suite 395  
Austin, TX 78759  
512.331.4115  
www.capitalareaspeech.com
Capital Texas Speech Pathology Services
*clinic and home-based*
2525 Wallingwood, Bldg 2
Austin, TX 78746

8500 Bluffstone Cove Bldg B Suite 105
Austin, TX 78759
512.327.6179
www.centraltexasspeech.com

Children’s Therapy Gym @ Seton Cedar Park Healthcare
*clinic-based*
801 E. Whitestone Blvd.
Cedar Park, TX 78613
512.324.5311

Children’s Therapy Services, PLLC
*home-based*
1601 Bell Springs Rd
Dripping Springs, TX 78620
Austin, TX
512.331.1999
www.homeCTS.com

Circle of Care Pediatric Home Health Services
*home-based*
23535 IH-10 W Suite 1201
San Antonio, TX 78257
512.615.9004
www.circlecare4kids.com

Dell Children’s Outpatient Pediatric Therapy Program, Anderson Outpatient Rehabilitation Center at Dell Children’s Medical Center
*clinic-based*
4900 Mueller Blvd.
Austin, TX 78723
512.324.0138
www.dellchildrens.net

Evolve Physical Therapy
*clinic-based*
1103 Cypress Creek Rd, Suite 103
Cedar Park, TX 78613
512.918.0044
www.evolvept.com
Growing Places Therapy Services, PLLC
*home-based*
12524 Capella Trail
Austin, TX 78732
512.587.5671
www.growingplacestherapy.com

KidSensations
*clinic-based*
3109 Slaughter Lane West
Austin, TX 78748
512.233.4000

KidTherapy Rehabilitation Center
*clinic-based*
4607 Manchaca Rd.
Austin, TX 78745
512.916.1511
www.kidtherapyaustin.com

Language and Movement
*clinic-based*
111 W. Anderson Ste C 100
Austin, TX 78752
512.451.0961
www.languagemovement.com

Little Tesoros Therapy Services
*clinic and home-based*
9101 Burnet Rd #103
Austin, TX 78758
512.248.2422
www.littletesoros.com

OT Connection
*clinic-based*
1433 Grand Avenue Pkwy #301
Pflugerville, TX 78660
512.251.3230
www.otconnection.com

Red Wagon Children’s Therapy
*clinic-based*
6507 Jester Blvd, Suite 309
Austin, TX 78750
512.343.1200
www.redwagontherapy.com
Hippotherapy is a unique form of therapy that uses horseback riding to address sensory, motor, and perceptual deficits.

Most hippotherapy facilities are non-profit organizations that provide hippotherapy services and other therapeutic riding opportunities.
Clients pay for services through a variety of means such as direct payments, CLASS or other Medicaid waiver programs, state agencies such as DARS, or private insurance. They provide services for children and adults with all types of physical and cognitive disabilities. Many meet strict industry standards and are affiliated with NARHA (North American Riding for the Handicapped Association). Check with organizations for additional details.

**AWARE Ranch**  
1708 Center Point Road  
San Marcos, TX 78666  
512.754.6773

**Dream a Dream Therapeutic Horsemanship**  
23650 Round Mountain Circle  
Leander, Texas 78641  
512.260.5957

4918 Bee Creek Rd  
Spicewood, Texas 78669  
512.966.0578  
www.dadth.org

**The HELP Center of Austin (Handicapped Equestrian Learning Program)**  
2908-B Gregg Lane  
Manor, TX 78653  
512.251.1099  
www.helpcenterofaustin.org

**Open My World Therapeutic Riding Center**  
1020 CR270  
Leander, TX 78641  
512.259.6665  
www.openmyworld.org

**RED Arena**  
1601 Bell Springs Rd  
Dripping Springs, TX 78620  
512.331.1999  
www.redarena.org

**R.O.C.K. Ride On Center for Kids**  
2050 CR 110  
Georgetown, Texas 78627  
512.930.7625  
www.rockride-org.doodlekit.com
AQUATIC THERAPY

Blue Sky Abilities
Community-based: No dedicated pool, but will come to community pools or home pool setting.
P.O. Box 151173
Austin, TX 78715
512. 924.1111
www.blueskyabilities.com

Dell Children’s Aquatic Therapy Program, Anderson Outpatient Rehabilitation Center at Dell Children’s Medical Center
Dedicated pool on site
4900 Mueller Blvd.
Austin, TX 78723
512.324.0138
www.dellchildrens.net

Kara Swinney, MS, PT at Sammy’s House
Dedicated pool located at Sammy’s House
2415 Twin Oaks Drive
Austin, TX 78757
E-mail: kara@homects.com
512.970.7792

Lakeway Aquatics Therapy & Wellness Center
Dedicated pool on site
1927 Lohman’s Crossing, #100
Lakeway, TX 78734
512.261.0620
Barker Keith Clinical Director
E-mail: barker@lakewayaquatics.com
E-mail: reception@lakewayaquatics.com
http://www.lakewayaquatics.com/

Reavis Rehab
Dedicated pool on-site
1208-Q North IH-35
Round Rock, TX 78681
512-310-POOL (7665)

Note: Reavis will be moving its physical location in December of 2010.
The new address will be
1250 S. AW Grimes Blvd.
Round Rock, TX 78664
RECREATION AND RESPITE

Respite is a planned break for the caregiver. It is a time when another person is caring for your child. The respite opportunities below are primarily in the form of camps. Other paid, respite opportunities may be provided in-home through Waiver Programs. See page 18.

Austin Resource Center for Independent Living (ARCIL)
Transition, information, advocacy, referrals: ARCIL, Inc. of Austin, Texas provides independent living services to persons with disabilities, their families and communities throughout Travis and surrounding counties. ARCIL also provides services throughout Hays, Caldwell, Comal and Blanco counties at ARCIL San Marcos (San Marcos, Texas), and Williamson, Bell, Burnett and Milam counties at ARCIL Round Rock (Round Rock, Texas).

825 E. Rundberg, Suite E6
Austin, Texas 78753
512-832-6349 or 1-800-414-6327
email: arcil@arcil.com
http://www.arcil.com/

Children’s Association for Maximum Potential
The Children’s Association for Maximum Potential (CAMP) serves children and adults with disabilities and special health care needs. They provide a wide range of recreational, educational, and respite services. CAMP does its best to ensure that no one is turned away based on the severity of their disability or the inability to pay. Central to each CAMP program is the provision of medical support, ensuring that everyone, regardless of the degree of medical needs, will be able to participate in all activities.

P.O. Box 27086
San Antonio, TX
210.671.5411
www.campcamp.org
Danny G. McBeth Recreation Center
Located in Zilker Park, this fully accessible facility has a multipurpose room, kitchen/craft room, game room, outdoor picnic areas, accessible playscape, and sand play area. They offer adapted recreation activities throughout the year for children and a recreational day program for adults with disabilities. They also offer adapted sports programs in tennis, swimming, cycling, basketball, rowing, dance and more.

2401 Columbus Drive
Austin, TX 78746
512.974.9011
www.ci.austin.tx.us/parks/mcbeth.htm

Down Home Ranch
Down Home Ranch, a working farm and ranch, is home to about 40 adults and children with disabilities. They offer summer camps and weekend respite camps for physically and emotionally healthy individuals age 13 or older with mild to moderate intellectual disabilities.

20250 FM 619
Elgin, TX 78621
512.856.0128
www.downhomerranch.org

Easter Seals Central Texas Camp ESKIMO
Camp ESKIMO (Easter Seals Kids In Motion) is a therapeutic day camp in Austin. They offer many adapted activities for children 5-15. Payment offered on a sliding scale.

1611 Headway Circle Building 2
Austin, TX 78754
512.478.2581
centraltx.easterseals.com

Extend-A-Care For Kids
Extend-A-Care for Kids offers affordable, license afterschool care at various school campuses in the Austin area. Call for level of care available on your child’s campus.

55 North IH 35
Austin, TX 78702
Main Number: 512.472.9402
http://eackids.org/
Executive Director
Joan Altobelli
512.226.8274
jaltobelli@eackids.org

The Flying Vikings
The Flying Vikings is a non-profit organization that provides free 20-30 minute plane rides to children with special needs or serious illness. During these rides the child becomes the pilot. Lunch and arts/crafts activities are also provided. Visit website for calendar or to contact.

flyingvikings.org
Email: flyinglittlevikings@yahoo.com

Miracle League
The Miracle League is a baseball league for children 4 – 19 with physical and cognitive disabilities. Games are two innings and last about an hour. Everybody bats, nobody is out, everybody scores, and everybody wins! Players are paired with “buddies”, middle or high school age peers who protect them on the field and facilitate player participation.

P.O. Box 200277
Austin, TX 78720
512.335.7434
www.miracle.tandcsports.org

Morgan’s Wonderland
A 25-acre fully accessible amusement park for children and adults with special needs, their family members, caregivers, and friends. Individuals with special needs are admitted free and those accompanying are admitted for $5. Reservation made by phone or online required.
5223 David Edwards Dr
San Antonio, TX 78233
210.495.5888
www.morganswonderland.com
**Sammy's House**
Sammy's House is a child development center for children who are medically fragile or have developmental disabilities. They offer a day program and periodic weekend respite programs in an inclusive environment with low child-to-adult ratios as well as a therapy equipment loan program.

2415 Twin Oaks  
Austin, TX 78757  
512.453.5258  
www.sammyshouse.org

**Special Olympics Central Texas (Region 13)**
Special Olympics Texas offers year-round sports training and competition in 22 Olympic-type sports for children and adults.

7715 Chevy Chase Drive, Suite 120  
Austin, TX 78752  
512.835.9873  
www.sotx.org/about/areas/area13

**Starlight Children's Foundation**
An organization that serves to network seriously ill children and their families through activities and outings, technology and education. They offer outpatient, community-based, and hospital-based activities.

Austin Office  
PO Box 92191  
Austin, TX  78709  
Contact: Glenda Skinner 512.912.6782  
E-mail: glenda.skinner@starlight.org  
www.starlight.org/texas

**VSA arts of Texas**
VSA arts of Texas (Vision • Strength • Access Arts for All) is a 501(c)(3) nonprofit organization that strives to create a society where people with disabilities learn through, participate in, and enjoy the arts. We are dedicated to the mission of promoting the creative power in people with disabilities by working with all community members to facilitate full access to the cultural and educational arts. VSA arts of Texas is a member of the international network of VSA arts, an affiliate of The John F. Kennedy Center for the Performing Arts.
VSA host an accessible and artistically stimulating Arts Festival each Spring.

3710 Cedar Street #7
Austin, Texas 78705
Local phone: 512-454-9912
Toll free: 1-866-489-8412
Email: info@vsatx.org
http://vsatx.org/

NURSING AGENCIES

As of the date of publication the following nursing agencies provide services to pediatric clients.

**Epic MedStaff**
3721 Executive Center, Suite 205
Austin, Texas 78731
512.372.3777, 877.899.3742
www.epicmedstaff.com

**First Choice Children’s Home Care**
3508 Far West Boulevard, Suite 130
Austin, Texas 78731
512.346.5273
www.ehhi.com

**Maxim Healthcare**
3737 Executive Center Drive, Suite 250
Austin, TX 78731
512.340.0171
www.maximhealthcare.com

**Medical Staffing Network**
33030 Northland Drive, Suite 312
Austin, TX 78731
512.459.5656
www.MSNNurse.com

**PSA Healthcare**
14205 N. Mopac Expressway, Suite 640
Austin, TX 78728
512.248.0400
www.psahealthcare.com
DURABLE/HOME MEDICAL EQUIPMENT

The following equipment companies vary in the types of services they provide. Many companies work with a combination of the following: feeding & nutritional (including enteral), incontinent & urinary, respiratory, oxygen, wound care, mobility/positional, and other home adaptive aids. Call or visit websites for specific information. Pediatric tracheostomy and ventilator support is noted.

All-Star Medical
1101 W. Pecan #8
Pflugerville, TX 78660
512.251.5977
www.allstarmedical.org

A&P Quality Care
5555 N. Lamar
Austin, TX 78751
512.452.5111
www.apqualitycare.net

Austin Wheelchair & Medical Supply Co.
5555 Lamar #D-111
Austin, TX 78751
512.452.7988
www.austinwheelchair.com

National Seating & Mobility
2211 Denton Drive, Suites G, J, & L
Austin, TX 78758
512.833.9956
www.nsm-seating.com

Patient Support Services
4310 McKnight Road
Texarkana, TX 75503
512.989.4881
www.pssi-midsouth.com

Pediatric Specialists
Will provide pediatric trach/vent supplies.
800 Paloma Dr. Bldg 6 Suite 140
Round Rock, TX 78664
512.671.9600, 877.515.4697
Travis Medical
*Will provide pediatric trach supplies.*
1104 W. 34th Street
Austin, TX 78705
512.458.4589
www.travismedical.com

United Rehab Specialists
1-888-295-4690
E-mail: Customerservice@united-rehab.net
www.united-rehab.net/index.php

Walgreens Home Care
*Will provide pediatric trach/vent supplies.*
9233 Waterford Centre Blvd, Suite 200
Austin, TX 78758
512.302.1411
www.walgreenshealth.com

The following are non-profit organizations that provide assistance with equipment.

Disabled Children’s Relief Fund (DCRF)
Provides equipment, prostheses, and rehabilitative services through grants.

P.O. Box 89
Freeport, NY 11520
516.377.1605
www.dcrf.com

Project MEND
Assists Texas families in purchasing equipment, ages 0-18.

1201 Austin Street
San Antonio, TX 78208
888.903.6363
www.projectmend.org
RELIGIOUS AND SPIRITUAL RESOURCES

Austin Ridge Bible Church
Austin Ridge Bible has a buddy system called Shadow Ministry. They work towards integration with the congregation, but they also offer a separate classroom for special needs children if necessary.

9300 FM 2244
Austin, TX 78733
512.263.7701
www.austinridge.org

Contact: Georgi Duwe, Shadow Ministry Coordinator
512.345.0202
email: georgi@georgiduwe.com

Bannockburn Baptist
Offers a buddy system to integrate children into Sunday School and the congregation. The pastor and his wife facilitate a support group for parents of special needs children. They also offer a respite night every other month and a special needs expo. See website for details and dates.

7100 Brodie Lane
Austin, TX 78745
512.892.2703
www.bbcfamily.com

Contact: Amy Louis, Special Needs Director
512.892.2703 ext. 237
e-mail: amyl@bbcfamily.com

Brentwood Oaks Church of Christ
Special needs ministry includes five teams of parishioners who take turns weekly providing care for children with special needs while families attend service.

11908 North Lamar Boulevard
Austin, TX 78753-2143
512.835.5982
www.brentwoodoaks.org
Contact: Jackie Boyd
512.835.5980

Chittamani Buddhist Center
A Buddhist study and meditation center. Does not offer specific programs but will work with families to meet individual needs.

1918 Bissel Lane
Austin, TX 78745
512.916.4444
www.meditationinaustin.org

First Evangelical Free Church
4220 Monterey Oaks Boulevard
Austin, TX 78749
512.891.1600
www.fefc.org
Contact: Lea

Grace Covenant Church
Offers a buddy system within their Special Needs Ministry.

9431 Jollyville Road
Austin, TX 78759
512.345.7840
www.grace360.org
Contact: Krista Sherwood

Hill Country Bible Church
Buddy program with integration or a self-contained classroom.

12124 RR 620 North
Austin TX 78750
512.331.5050
www.hcbc.com
Contact: Terri Beck
e-mail: specialneeds@hcbc.com

Jewish Family Service Initiatives and Groups
Jewish Family Service is an initiative of The Jewish Community Association of Austin. They maintain an online resource guide with current information on a wide range of congregational support for children and adults with disabilities, including integrating buddy systems, camps, early childhood support, and adaptive support for blind/deaf community, and national resource links.
Westover Hills Church of Christ
Offers a buddy system as well as a special room for children if necessary. Westover Hills also has an outreach ministry working with the deaf community.

8332 Mesa Drive
Austin, TX 78759
512.345.6386
www.westover.org

Palliative Care

Palliative Care is a holistic model of care that addresses the Medical, Psycho-social, and Spiritual needs of the child and family. Palliative Care consult is available, from diagnosis to end-of-life, to families whose children have life-limiting illness.

Dell Children’s Medical Center Palliative Care
Dell Children’s offers inpatient and outpatient palliative care services through Dell Children’s Medical Center and through the Marni Paul Specialty Care Center.

For more information: 512.324.0197
http://www.dellchildrens.net/services_and_programs/palliative_care
END OF LIFE PLANNING AND SUPPORT

Information

Austin Memorial & Burial Information Society (AMBIS)
AMBIS provides education and assistance with advance directives. It is a local volunteer run non-profit organization helping residents of Central Texas make funeral and memorial arrangements.

P.O. Box 4382
Austin, Texas 78765
512.480.0555
www.fcaambis.org

Hospices

Hospice Austin
4107 Spicewood Springs Road, Suite 100
Austin, TX 78759
512.342.4700
www.hospiceaustin.org

Hope Hospice
Provides service to Bexar, Caldwell, Comal, Guadalupe, and Hays counties.

611 North Walnut Avenue
New Braunfels, TX 78130
830.625.7795 or 830.625.7525
www.hopehospice.net

Odyssey Hospice of Austin
4201 West Parmer Lane, Bldg C Suite 100
Austin, TX 78727
512.310.0214
www.odyssey-healthcare.com
Bereavement Support

For the Love of Christi
Offers bereavement support for children, teens and adults. Members attend groups based on the nature of their loss. Bilingual support and educational workshops also provided.
2306 Hancock Drive
Austin, TX, 78756
512.467.2600
www.fortheloveofchristi.org

Griefshare
Offers bereavement support for adults. Groups meet at churches around the nation and use a religious Christian curriculum. Go to their website to find locations near you.
www.griefshare.org

Hospice Austin
Offers bereavement support for adults and children in several different group settings. They offer brief individual counseling, educational resources, and a short summer camp for children who have experienced loss. Spanish bereavement support available.
4107 Spicewood Springs Road, Suite 100
Austin, Texas 78759
512.342.4700 or 800.445.3261
www.hospiceaustin.org

My Healing Place
Offers support for bereavement and ongoing loss. They have adult and child support groups, family and individual counseling as well as consultation services and educational resources.
2130 Guadalupe
Austin, TX. 78705
512.472.7878
www.myhealingplace.org
The Compassionate Friends
International support system for families who have lost children. The local chapters offer support groups and local referrals. On their website you can find resources for parents, siblings, and grandparents. Compassionate Friends has no religious affiliation and offers any level of support needed.
877.969.0010
www.compassionatefriends.org

Local Chapter:
TFC of Georgetown
Mary Anne 512.869.0077
Cheryl 201.781.2452
email: tcfgeorgetowntx@gmail.com
Meetings: 3rd Tuesday of each month 7-9 pm
Meeting Address:
The Worship Place
811 Sun City Blvd
Georgetown, TX 78633
Index
A&P Quality Care................................................. 39
(AAP) American Academy of Pediatrics.............. 6
Acronyms for State Agencies ........................... 13
Advocacy, Inc.................................................. 22, 23
All-Star Medical............................................... 39
AMBIS .................................................................. 44
American Academy of Pediatrics ...................... 6
Amerigroup....................................................... 14, 15
Any Baby Can Child and Family Resource Center ........ 24
Aquatic Therapy.................................................. 33
Austin Resource Center for Independent Living (ARCIL) ................. 23, 24
Arc of the Capital Area....................................... 23, 24
Austin ISD Parent Liaison.................................... 27
Austin Memorial & Burial Information Society .... 44
Austin Resource Center for Independent Living ................. 23, 24
Austin Ridge Bible Church................................. 41
Austin Travis County Integral Care...... 19, 20, 21, 25
Austin Wheelchair & Medical Supply Co. ............... 39
Austin’s Communication Station......................... 28
Autism .............................................................. 4, 8, 26
Autism Speaks .................................................... 4
AWARE Ranch................................................... 32
Bannockburn Baptist.......................................... 41
Bereavement...................................................... 2, 45
Blue Sky Abilities............................................... 28, 33
Bluebonnet Trails Community
MHMR Center ..................................................... 19, 20, 21, 25
Brentwood Oaks Church of Christ ............... 41
CAMP ............................................................ 34
Camp ESKIMO.................................................. 35
Candlelighters Childhood Cancer Program............. 9
Capital Area Speech........................................... 28
Capital Texas Speech Pathology Services, Inc............. 29
Caregiver Support Group for Parents and Family Members of Children with Complex Chronic Conditions ............................................................. 9
Cerebral Palsy..................................................... 7
(CCP) Comprehensive Care Program ............. 15
(CChIPAG) Complex Chronic Illness Parent Advisory Group .................................................. 10
Children Association for Maximum Potential ...... 34
Children Health Insurance Plan ..................... 16
Children Therapy Gym....................................... 29
Children Therapy Services, PLLC ...................... 29
Children with Special Health Care Needs ........... 17
(CHIP) Children Health Insurance Program Division .................................................. 16
Chittamani Buddhist Center .......................... 42
Church Ministries .................................... 41
Circle of Care Pediatric Home Health Services ... 29
Community Care Services ....................... 18, 19, 21
Community Living Assistance and Support Services (CLASS) .................. 18
Compassionate Friends ............................... 46
Comprehensive Care Program (CCP) .............. 15
(CSHCN) Children with Special Health Care Needs ............................ 17
Danny G. McBeth Recreation Center ........... 35
(DBMAT) Deaf Blind Multi Handicapped Association of Texas .................. 7
(DCRF) Disabled Children Relief Fund .......... 40
def. and Hard of Hearing Services .......... 20
Deaf Blind Multi-Handicapped Association of Texas .................. 7
Dell Children’s Aquatic Therapy ............... 33
Dell Children’s Outpatient Pediatric Therapy Program ................................ 29
Dell Children’s Pediatric Palliative Care ........ 43
Disability Policy Consortium ............... 24
Disabled Children Relief Fund .................. 40
Division of Blind Services .................. 20
(DME) Durable Medical Equipment .......... 39
Down Home Ranch ................................. 35
Down Syndrome Association of Central Texas ... 10
Dream a Dream Therapeutic Horsemanship ..... 32
Durable/Home Medical Equipment .......... 39
Eanes ISD Parent Liaison ..................... 27
Early Childhood Intervention (ECI) .......... 2, 12, 24
Easter Seals Central Texas ..................... 25, 35
ECI Homespun ........................................ 25
ECI PRIDE Program ................................. 25
Education Service Center Region XIII ......... 22
Educational Resource Center on Deafness .... 27
End-of-Life ............................................... 2
Epic MedStaff ......................................... 38
Epilepsy Family Support Group .................. 10
(ESC XIII) Education Service Center Region XIII ... 22
Estate and Financial Plans for Special Needs ... 22
Evercare .................................................. 15
EveryChild, Inc. ....................................... 7
Evolve Physical Therapy ......................... 29
Exceptional Parent Magazine ................. 4
Extend-a-Care ........................................ 35
Family Support Cooperative .................... 11
Family Voices ......................................... 4
Fathers Network .................................... 5
First 100 Days Kit .................................. 4
First Choice Children’s Home Care ............. 38
First Evangelical Free Church .................. 42
Flying Vikings ....................................................... 36
For the Love of Christi .......................................... 45
Georgetown ISD Parent Liaison .......................... 27
Grace Covenant Church ...................................... 42
Grief...................................................................... 45
Griefshare ............................................................ 45
Growing Places Therapy, Services, PLLC........... 30
Hays CISD Parent Liaison ................................ 17
(HHSC) Health and Human Services... 13
Hill Country Bible Church .................................. 42
Hill Country Community MHMR Center.................. 19, 20, 21, 25
Health Insurance Premium Payment (HIPP) ... 12, 16
HELP Center of Austin ......................................... 32
Hippotherapy .................................................... 2, 31
Home and Community-Based Services ........... 19
Hope Hospice .................................................... 44
Hospice Austin .................................................... 44, 45
IAN Community .................................................. 5
In Home and Family Support (IH&FS) ............... 21
Institute for Family-Centered Care .................... 5
Jewish Family Service ......................................... 42
Kara Swinney, Aquatic Therapy ....................... 33
Kidsensations .................................................... 30
Kid Therapy Rehabilitation Center .................. 30
Language and Movement .................................. 30
Leander ISD Parent Liaison ................................. 27
Leukodystrophy ................................................... 7
Little Tesoros Therapy Services ....................... 30
Maxim Healthcare .............................................. 38
McBeth Recreation Center ................................. 35
Medicaid Managed Care ................................. 14, 15
Medicaid Transportation .................................. 23
Medicaid Waivers Programs ............................. 18
Medicaid, HHSC ............................................... 14
Medical Staffing Network .................................. 38
Medically Dependent Children Program (MDCP) . 18
Medically Needy Program ................................. 14, 16, 17
Mental Health and Mental Retardation Authority ... 13
(MRSD) Mental Retardation Services Department ................................ 19
Metro Access .................................................... 23
(MHMRA) Mental Health and Mental Retardation Authority ................................ 13
Miracle League ................................................... 36
Mitochondrial Disease ......................................... 7
My Healing Place ............................................. 45
National Center of Medical Home Initiatives for Children with Special Needs .......... 6
National Dissemination Center for Children with Disabilities ........................................ 6

49
<table>
<thead>
<tr>
<th>Organization</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Organization of Rare Disorders (NORD)</td>
<td>6</td>
</tr>
<tr>
<td>National Parent to Parent Network</td>
<td>5</td>
</tr>
<tr>
<td>National Seating and Mobility</td>
<td>39</td>
</tr>
<tr>
<td>Non-educational Funding</td>
<td>22</td>
</tr>
<tr>
<td>Odyssey Hospice of Austin</td>
<td>44</td>
</tr>
<tr>
<td>Open My World Therapeutic Riding Center</td>
<td>32</td>
</tr>
<tr>
<td>OT Connections</td>
<td>30</td>
</tr>
<tr>
<td>Palliative Care</td>
<td>2, 3, 43</td>
</tr>
<tr>
<td>Parent Support</td>
<td>2</td>
</tr>
<tr>
<td>PATH Project</td>
<td>26</td>
</tr>
<tr>
<td>Patient Support Services</td>
<td>39</td>
</tr>
<tr>
<td>Pediatric Specialists</td>
<td>39</td>
</tr>
<tr>
<td>Pflugerville ISD Parent Liaison</td>
<td>28</td>
</tr>
<tr>
<td>Primary Home Care Community</td>
<td></td>
</tr>
<tr>
<td>Care Services (PHC)</td>
<td>21</td>
</tr>
<tr>
<td>Private Health Insurance</td>
<td>12</td>
</tr>
<tr>
<td>Program Health Insurance Premium</td>
<td></td>
</tr>
<tr>
<td>Payment Reimbursement</td>
<td>12, 16</td>
</tr>
<tr>
<td>Project MEND</td>
<td>40</td>
</tr>
<tr>
<td>PSA Healthcare</td>
<td>38</td>
</tr>
<tr>
<td>Rare Diseases</td>
<td>6</td>
</tr>
<tr>
<td>R.O.C.K. Ride On Center for Kids</td>
<td>32</td>
</tr>
<tr>
<td>Reavis Rehab</td>
<td>33</td>
</tr>
<tr>
<td>RED Arena</td>
<td>32</td>
</tr>
<tr>
<td>Rhythm of Life Music Therapy</td>
<td>31</td>
</tr>
<tr>
<td>Round Rock ISD Parent Liaison</td>
<td>28</td>
</tr>
<tr>
<td>Sammy's House</td>
<td>37</td>
</tr>
<tr>
<td>School District Parent Liaison, Special Ed.</td>
<td>27</td>
</tr>
<tr>
<td>Sibling Support Project</td>
<td>6</td>
</tr>
<tr>
<td>Speak Freely</td>
<td>31</td>
</tr>
<tr>
<td>Special Needs Neighborhood</td>
<td>11</td>
</tr>
<tr>
<td>Special Olympics Texas</td>
<td>37</td>
</tr>
<tr>
<td>Supplemental Security Income (SSI)</td>
<td>13</td>
</tr>
<tr>
<td>SSI for Low-Weight and Premature Infants</td>
<td>13</td>
</tr>
<tr>
<td>Starlight Foundation</td>
<td>37</td>
</tr>
<tr>
<td>STAR Program</td>
<td>14</td>
</tr>
<tr>
<td>STAR+PLUS</td>
<td>15, 16</td>
</tr>
<tr>
<td>Starbright Pediatric Rehabilitation Clinics</td>
<td>31</td>
</tr>
<tr>
<td>State Agency Acronyms</td>
<td>13</td>
</tr>
<tr>
<td>Superior</td>
<td>14</td>
</tr>
<tr>
<td>Supplemental Security Income</td>
<td>13</td>
</tr>
<tr>
<td>(TEA) Texas Education Agency</td>
<td>25</td>
</tr>
<tr>
<td>Texas Autism Advocacy</td>
<td>8</td>
</tr>
<tr>
<td>Texas Center for Disability Studies, University of Texas at Austin</td>
<td>8</td>
</tr>
<tr>
<td>Texas Child Study Center</td>
<td>11</td>
</tr>
<tr>
<td>Texas Council for Developmental Disabilities</td>
<td>8</td>
</tr>
<tr>
<td>Texas Department of Aging and Disability Services</td>
<td>20</td>
</tr>
<tr>
<td>Texas Department of Assistive and Rehabilitative Services</td>
<td>13</td>
</tr>
<tr>
<td>Texas Department of Insurance</td>
<td>12</td>
</tr>
</tbody>
</table>
Texas Department of State Health Services...... 13
Texas Education Agency Parent
Special Education ........................................ 25
Texas Education Law.................................26
Texas Health Steps, TxDSHS Children and
Pregnant Women.......................................15
Texas Home Living Waiver .........................19
Texas Parent to Parent ................................9
Texas School for the Blind and Visually Impaired 26
Texas School for the Deaf............................26
Texas Technology Access Project................. 9
Therapeutic Riding......................................31
Therapy ..................................................2, 29, 30, 31
Therapy Center of Buda...............................31
Total Communication ..................................31
Travis Medical ...........................................40
(TSBVI) Texas School for the Blind and
Visually Impaired .................................... 26
(TSD) Texas School for the Deaf ................. 26
(TTAP) Texas Technology Access Project .......9
(TxCDD) Texas Council for Developmental
Disabilities ..............................................8
(TxDADS) Texas Department of of Aging
and Disability ........................................... 13,20
(TxDARS) Texas Department of Assistive
and Rehabilitative Services ......................... 13,20
(TxDSHS) Texas Department of State
Health Services .........................................13
(TxHmL) Texas Home Living Waiver .......... 19, 20
(Txp2p) Texas Parent to Parent......................9
U.R. Our Hope ..........................................11
Undiagnosed Illness ....................................11
United Cerebral Palsy Association ............... 7
United Leukodystrophy Foundation (ULF)..... 7
United Mitochondrial Disease Foundation (UMDF)..7
United Rehab Specialists ......................... 40
VSA Arts of Texas ......................................37
Walgreen’s Home Care ................................40
Westover Hills Church of Christ ................. 43
Wrights Law ...........................................25
For more information about CChIPAG, contact—

CChIPAG Coordinator
Kendra Koch
cchipag@seton.org

Much Thanks to the parents of the CChIPAG Steering Committee for their efforts on this project:

Aide Benson
Nicole Castro
Catherine Kennedy
Kendra Koch
Debbie Luzzo
Jennifer McKay
Bethany Miller
Brian Miller
Michelle Mirsky
Diane Stonecipher

Special thanks to Bethany Miller who coordinated this project.

Funding for printing of this guide was provided by a grant from the State of Texas, Department of State Health Services, Children with Special Health Care Needs Services Program.
Mission Statement

The Complex Chronic Illness Parent Advisory Group exists to enhance and strengthen existing supports for children with Complex Chronic Illness and their families, and to identify and address areas where support is needed. We will work collaboratively with Dell Children’s Medical Center, DCMC Palliative Care, and the broader community to be an ongoing force that creates a unified voice for the many unheard that we represent.