transitioning to neurology adult care:

age 15 guide











Transitioning to Adult Care

Dear Patient Family,

The transition from being a teen to a young adult is both challenging and rewarding. During this transition, our teenage patients will reach a time when they are best cared for by doctors that focus on adult healthcare. This transition from pediatric to adult healthcare most often happens when our patients are between the ages of 18 and 21.

Your Children's Health Medical Team will help you and your family make a transition plan during clinic visits. This plan may include:

- Building skills and knowledge to help manage your young adult's health
- Making choices about medical care
- Having insurance coverage
- Reaching goals for the future.

We will talk to you about the timing of the move from pediatric to adult healthcare. When it is the right time to move to adult healthcare, your Children's Health Medical Team will help:

- Find an adult doctor
- Send medical records to the new adult doctor
- Talk to the new adult doctor about your young adult's health needs.

At the age of 18, teens become legal adults and will have to give permission for us to share personal health information with family members. Without their permission (or consent), we will not be able to talk about their healthcare with their family. Some young adults have health conditions that prevent them from making choices about their health. We can help families of these young adults learn about their options for supported decision-making.

We know it can be hard to move to a new adult doctor. Your Children's Health Medical teams wants you and your family to be ready for this change and is here to help you make the transition to adulthood. Please talk to us if you have any questions or concerns.

Best Wishes,

Your Children's Health Medical Team



Contents

Checklist	3
About Healthcare Transition	5
Journey Map	7
Texas Medicaid Waiver Programs	9
Special Needs Trust and Texas ABLE Program	18
Social Security Disability Income (SSDI)	19
Social Security Income (SSI)	20
Adaptive Sports for Children and Teens	22
Respite Care Resources	24
Attendant Care Services	26
Day Habilitation	28
School Services – Parent Guide for Special Education	31
What is a Transition Assessment	34
How to Get a Drivers License with Adaptations	35
Vocational Rehabilitation Program	37



Age 15 Checklist

Health and Wellness:

Learning how to manage health and wellness is key to transitioning to adult care (for health care transition). The first step in your child taking charge of their care is them knowing about their health condition and medicines, as they are able. Help your child:

- Learn about their health condition, health history, and signs and symptoms.
- Learn about their medicine, including names, amount, and reason they take each one.
- Learn about any special medical equipment and home health services they use.

Health Insurance:

- If your child gets services from a Medicaid waiver program, talk with your service coordinator about any changes to services that my take place after your child turns 18.
- If your child is not receiving services from Medicaid waiver program, sign-up for the waiver programs by getting your child on the interest (wait) list now or as soon as possible.

Future Planning:

- Start planning ahead. When your child turns 18, Supplemental Security Income
 (SSI) will no longer use your income and resources. Instead, they will use child's
 income and resources to decide eligibility. Review banks and financial planning to
 ensure no money is being saved in the child's name in preparation for SSI
 application when the child turns 18. Receiving the funds directly may cause the child
 to lose benefits, such as Supplemental Security Income (SSI) and Medicaid.
- Consider a Special Needs Trust and /or Texas ABLE program.

Respite/Housing Programs:

- Find special recreational programs in your area that meet your child's needs. This could include Special Olympics, Best Buddies, art, music, and theater programs.
- If you do not already have respite care, explore options through your waiver program or other community services.
- Begin researching day programming and long-term housing options for when your child is an adult. Finding the right program for your child can take time and waiting lists can be long.

Education-School Planning:

- Make sure your child is receiving life skills planning, and if appropriate, vocational training as a part of their Individualized Education Program (IEP) or transition plan.
- Talk to your care team to see if a referral for a functional transition assessment would be helpful. The assessment is offered by Children's Health Rehabilitation and Therapy Services (CHRTS).



Programs and Foundations:

- Research and connect with parent groups in your community to start to build a
 network of resources to help you with transition process. While this is not a
 comprehensive list, many of the following organizations have local chapters offer
 classes, and provide other resources that may be useful in the transition process:
 - Epilepsy Foundation of Texas: https://www.eftx.org/
 - Angelman Syndrome Foundation: https://www.angelman.org/
 - o Dravet Syndrome Foundation: https://dravetfoundation.org/
 - Lennox-Gastaut Syndrome (LGS) Foundation: https://www.lgsfoundation.org/
 - o International Rett Syndrome Foundation: https://www.rettsyndrome.org/
 - o Tuberous Sclerosis Complex (TSC) Alliance: https://www.tscalliance.org/
 - Look into other organizations or foundations that are specific to your child's diagnosis that can offer support and additional resources for transition.



About Healthcare Transition

Healthcare transition is the change from child (pediatric) healthcare to adult healthcare. This change includes moving to adult doctors and adult insurance. Below is a list to help plan for your healthcare transition.

- 1. Building knowledge about medical conditions and medications. This can begin early and includes learning:
 - Medical condition, medications, and medical history
 - Healthy wellness habits including diet, exercise, and sleep
 - Skills to help manage your health such as how to call for a medical appointment, how to fill a prescription, and what to do in an emergency.
- Determining who will make medical decisions.
 - At the age of 18, a teen becomes a legal adult.
 - An adult is responsible for making medical decisions such as giving permission for medical treatment and deciding who knows about your personal medical information.
 - If a child will not be responsible for making medical decisions as an adult, supported decision-making must be in place.
 - Examples of supported decision-making could include guardianship or medical power of attorney.
- 3. Finding and transferring care to an adult doctor.
 - Talk with your pediatric doctor about when a new adult doctor is needed.
 - Contact your health insurance company to help identify new adult doctors.
 - Ask your pediatric doctor to talk with your new adult doctor as you transfer your care.
- 4. Having health insurance to pay for healthcare.
 - Contact your health insurance company to find out when your health insurance will change and options for future health insurance.
 - Select new health insurance that will cover the costs of all medical needs.



Helpful Websites for Transition

General:

Children's Health: www.childrens.com

*Got Transition/Center for Health Care Transition: www.gottransition.org

*Navigate Life Texas: www.navigatelifetexas.org

*Texas Parent to Parent: www.txp2p.org

*Texas Department of State Health Services - Children with Special Health Care Needs:

www.dshs.texas.gov/mch/cshcn.aspx

*Texas Workforce Commission: www.twc.state.tx.us

Health Insurance:

*Health Insurance Marketplace: www.healthcare.gov

*Supplemental Security Income: www.ssa.gov/ssi

*Texas Health Insurance Premium Payment (HIPP): www.gethipptexas.com

*Texas Health Options: www.texashealthoptions.com

Medical Decision Making:

*Disability Rights Texas: www.disabilityrightstx.org

*Texas Law Help: www.texaslawhelp.org

Future Planning:

*Federal Student Aid: www.studentaid.ed.gov

Texas Education Agency (TEA): www.tea.texas.gov

*Think College!: www.thinkcollege.net

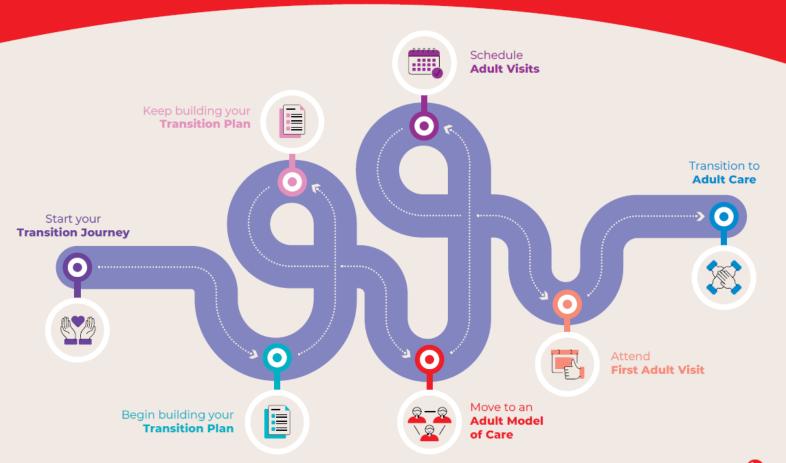
*U.S. Department of Education: www.ed.gov

*Website available in Spanish



your journey to health care transition

JOURNEY MAP



Making life better for children.





your journey to health care transition

JOURNEY MAP



Transition Planning Transition Planning Adult Model of Care

Transfer to
Adult Doctor

Transfer to

Adult Doctor

Transition to Adult Care



Start your Transition Journey

When it is time, you will work with your care teams to start your health care transition journey.

You will talk about:

What to expect

- during your transition.
- How to build a plan for transition.
- What age you will transition to adult doctors.
- Sign up for MyChart to get access to your medical records.



Begin building your **Transition Plan**

Your care teams will give you tools to:

- Learn about your medical condition, medicines and wellness.
- Decide who will be making your medical decisions after age 18 and if legal tools will be needed.
- □ Plan for your future: school, work and living situations.



Keep building your **Transition Plan**

As you build your transition plan, we will give you tools to:

- Practice skills to help you manage your health.
- Make medical decisions and have legal tools in place before you turn age 18.
- Make goals for your future.
- Learn about health insurance and decide how you will pay for health care in the future.
- ☐ Find new adult doctors.



Move to an Adult Model

- At the age of 18, start making your own medical decisions. You are now a legal adult.
- □ Care teams will ask you to sign consents. This gives permission for medical treatment.
- □ Care teams will ask you to sign a permission form. This tells us who we can share your personal health information with.

*These do not apply if another medical decision-making option or legal tool is in place.



Adult Visits

- ☐ Tell us when you have found new adult doctors. We can send a referral and copy of your medical records.
- Ask for a medical summary to give to your new adult doctors.
- Call your new doctors to schedule or confirm your upcoming visit.



First Adult Visit

- Be ready to complete "new patient" forms, sign consents and bring copies of medical decisionmaking and legal tools with you.
- Talk to your new care teams and ask questions.
- Understand your care plan and any updates or changes to your care.
- Make follow-up appointments, if your doctors tell you to.



Transition to Adult Care

- Fully transfer your care to your adult doctor.
- Continue visits to new adult doctors as needed.



Scan the QR code to visit our website

and learn more about transitioning to adult care.





Texas Medicaid Waiver Programs

What is a Medicaid Waiver program?

- A waiver program lets a state use money from Medicaid to give some long-term home and community-based services for children and adults with a disability and special health care needs.
- If your child is eligible, they can get the services they need in their own homes or other community settings.
- Most waiver programs are based on your child's disability or special health care need and their income (not the family's income).
- If your child gets services from waiver program, they also get Medicaid health insurance.
- In Texas, there are many waiver programs run by The Texas Health and Human Services Commission (HHSC) and the Department of State Health Services (DSHS).
- Thery are called "waivers" because certain Medicaid rules are waived (those rules are put aside).

What do I need to know?

- Sign-up for the waiver programs by getting your child on the interest (wait) list now or as soon as possible.
- Some waiver programs have long wait times to get services.
- Even if you are not sure your child will ever need these services, you should still get your child on the interest list to have these waiver programs as choices if your child needs them in the future.
- Get your child on all the waiver program interest lists that meet your child's needs.
 - Your child can be on more than 1 interest lists at a time but can only be getting services from 1 waiver program at a time.
 - You should get a letter to confirm your child has been put on a waiver program interest list.
 - The State may call you or send you a letter about the waiver programs you signed your child up for.

Things to remember:

- It is important you always answer the call, return the phone call, or respond to the letter or your child's name may be taken off the lists.
- If you apply in person or on the phone, get the names of the people you speak to and any other details they give you when you sign up. Keep it with your records.
- If your contact information (name, address, phone number) changes, call the waiver program to update your contact information.
- Call at least 1 time per year to make sure that your child's name is still on the interest list.
 - Many parents use their child's birthday as a date to call so they do not forget to call.



- o Ask where your child is on the interest list.
- Make sure that your contact information (name, address, telephone number) is still right.

For more information about waiver programs and how to join interest list, visit this website: https://www.navigatelifetexas.org/en/insurance-financial-help/texas-medicaid-waiver-programs-for-children-with-disabilities



Home and Community-based Services (HCS)

What is Home and Community-based Services (HCS)?

- HCS offers services and support to people with an intellectual disability (ID) or related condition (other health issues).
- Related conditions:
 - A disability (other than an ID) that starts before the age of 22 and will likely continue.
 - Must cause major limits with the person being able to function and cause limits like those of an ID.
 - Autism, Cerebral Palsy, Seizure Disorder and Spina Bifida are types of related conditions.
- HCS offers services and support so that people can live at home with their family, in their own home or in a community setting like a small group home.

How do I learn more about the HCS Waiver Program?

- Visit the following websites:
 - https://hhs.texas.gov/doing-business-hhs/provider-portals/long-term-care-providers/home-community-based-services-hcs
 - https://www.navigatelifetexas.org/en/insurance-financial-help/home-and-community-based-services-hcs

How do I get my child on the HCS interest list?

 Contact your county's Local Intellectual and Development Disability Authority (LIDDA). Find the LIDDA that serves your area by going to https://apps.hhs.texas.gov/contact/la.cfm.



Medically Dependent Children's Program (MDCP)

What is the Medically Dependent Children's Program (MDCP)?

- MDCP offers services to families caring for medically dependent children and young adults under the age of 21.
- MDCP serves as a different option than a nursing home.
 - Some children who are medically fragile (in a critical state of health) may be able to avoid the MDCP "interest list" through the Money Follows the Person (MFP) process.
 - When you call the MDCP interest list, ask to speak with the person who is an expert on Money Follows the Person.
- MDCP offers personal care services, private duty nursing, and varies therapies.

How do I learn more about MDCP?

- Visit the following websites:
 - https://hhs.texas.gov/doing-business-hhs/provider-portals/long-term-careproviders/medically-dependent-children-program-mdcp
 - https://www.navigatelifetexas.org/en/insurance-financial-help/medically-dependent-children-program-mdcp

How do I get my child on the MDCP interest list?



Community Living Assistance and Support Services (CLASS)

What is Community Living Assistance and Support Services (CLASS)?

- CLASS offers home-and community-based services to people with intellectual disabilities or **related conditions** who meet additional criteria.
 - A related condition is a disability, other than an intellectual disability, that starts before the age of 22 and that affects a person's ability to function in daily life.

How do I learn more about the CLASS Program?

- Visit the following websites:
 - https://hhs.texas.gov/doing-business-hhs/provider-portals/long-term-careproviders/community-living-assistance-support-services-class
 - https://www.navigatelifetexas.org/en/insurance-financial-help/communityliving-assistance-and-support-services-class

How do I get my child on the CLASS interest list?



Deaf-Blind with Multiple Disabilities (DBMD)

What is Deaf-Blind with Multiple Disability (DBMD)?

- DBMD offers home and community-based services to people who are deaf **and** blind **and** have many disabilities.
- The program helps by giving more opportunities for individuals to communicate and interact with their environment.
- Must have a been diagnosed before the age of 22.

How do I learn more about DBMD?

- Visit the following websites:
- https://hhs.texas.gov/doing-business-hhs/provider-portals/long-term-care-providers/deaf-blind-multiple-disabilities-dbmd

• https://www.navigatelifetexas.org/en/insurance-financial-help/deaf-blind-with-multiple-disabilities-dbmd

How do I get my child on the DBMD interest list?



STAR+PLUS Home and Community-based Services (HCBS)

What is STAR+PLUS Home and Community-based Services (HCBS)?

- STAR+PLUS HCBS helps people live at home rather than living in a nursing facility.
- If eligible for nursing facility care member can get acute care and long-term services and supports (LTSS) in order to live in the community.
- Offers services to members age 21 and older.
- Services offered include personal assistance services, habilitation, and other supportive services.

How do I learn more about HCBS?

- Visit the following website:
 - https://www.hhs.texas.gov/providers/long-term-care-providers/home-communitybased-services-hcs
 - https://www.hhs.texas.gov/services/health/medicaid-chip/med
 - https://www.navigatelifetexas.org/en/insurance-financial-help/starplus-home-andcommunity-based-services-hcbs

How do I get my child on the HCBS interest list?



Texas Home Living (TxHmL)

What is Texas Home Living (TxHmL)?

- Provides services to children and adults with an intellectual disability (ID) or a related condition who live in their own home or their family's home.
- Services offered include personal assistance services, habilitation, and other supportive services.

How do I learn more about TxHmL?

- Visit the following website:
 - https://www.hhs.texas.gov/providers/long-term-care-providers/texas-home-living-txhml
 - https://www.navigatelifetexas.org/en/insurance-financial-help/texas-home-livingtxhml

How do I get my child on the TxHmL interest list?

 Contact your county's Local Intellectual and Development Disability Authority (LIDDA). Find the LIDDA that serves your area by going to https://www.hhs.texas.gov/sites/default/files/documents/services/mental-health-substance-use/yes-waiver-inquiry-line.pdf



Youth Empowerment Services (YES)

What is Youth Empowerment Services (YES)?

- Helps with children between the ages of 3-9 with serious mental, emotional and behavioral difficulties.
- Helps keep child stay in the home and community.
- Services offered include respite services and other supportive services.

How do I learn more about YES?

- Visit the following website:
 - o https://www.hhs.texas.gov/providers/behavioral-health-services-providers/youth-empowerment-services-waiver-providers
 - o https://www.navigatelifetexas.org/en/insurance-financial-help/youth-empowermentservices-yes

How do I get my child on the YES interest list?

 Contact your county's Local Intellectual and Development Disability Authority (LIDDA). Find the LIDDA that serves your area by going to https://www.hhs.texas.gov/sites/default/files/documents/services/mental-health-substance-use/yes-waiver-inquiry-line.pdf



Special Needs Trust and Texas ABLE Program

Saving money for costs related to your child's disability may be helpful for their future. While there are many ways to do this, here are a couple options to consider:

Texas ABLE Program

- Texas ABLE (Achieving a Better Life Experience) Program gives Texans with disabilities and their families the chance to save money for disability-related costs.
- Money can be saved in a tax-advantaged account. This allows families to save money without losing their eligibility for certain government benefits such as Supplemental Security Income (SSI), Supplemental Security Disability Income (SSDI) and Medicaid.
- To be eligible, a person must be a Texas resident (lives in the State of Texas) who had their disability before age 26.
- To find out what other requirements need to be met contact Texas ABLE by calling 1-844-489-2253 or visit www.texasable.org

Special Needs Trusts

- A special needs trust can be set up to allow families to save money for costs related to their child's disability.
- It is important to talk to a lawyer with experience in helping families set up a special needs trust.



Social Security Disability Income (SSDI)

What is SSDI?

- SSDI pays benefits to children who have a disability that began before they turned age 22 and whose parent(s) get or received (if they are dead) Social Security retirement or disability benefits.
- SSDI is a "child's" benefit because it's paid based on a parent's Social Security earnings record.
- Sometimes it can also be a benefit for an adopted child, a stepchild, a grandchild or step-grandchild.

To learn more visit: **Social Security has helpful information visit their website at:** https://www.ssa.gov/planners/disability/qualify.html#anchor7

- Navigate Life Texas has helpful information visit their website at: https://www.navigatelifetexas.org/en/insurance-financial-help/ssi-benefits-for-children-with-disabilities
- Texas Parent to Parent has helpful information visit their website at: https://www.txp2p.org/services/services-for-parents-pathway-toadulthood/services-and-supports

Who can get SSDI?

- A child who has had 1 of their parents getting Social Security retirement or disability benefits.
- A child who has had a parent die and they worked enough to get Social Security.
- Must have a disability that started before 22.
- Someone who is not married.
- Someone under age 18 might get the money benefits of SSDI.
- They do not become eligible for Medicare until they are at least 18 years old. Once they are eligible, they go through a 2 year (24 months) qualifying period.

How to get SSDI?

- To apply, call the Social Security Administration at 1-800-772-1213 to make an appointment at the office closest to you.
- If you are deaf or hard-of-hearing, call the TTY number at 1-800-325-0778.
- To find your local Social Security Administration office, go to https://www.ssa.gov/locator/.



Supplemental Security Income (SSI) for Adults

What is SSI?

- SSI is a program through the government's Social Security Administration (SSA)
 that gives monthly cash assistance to help pay for your (if care for yourself) or your
 child's (if you have to care for your child) needs like clothing, food and shelter, and
 medical needs.
- People in Texas who are approved for SSI will also get Medicaid.
- To learn more, you can read this guide: https://www.ssa.gov/benefits/ssi/
 It will give you details about the program like benefits, who is eligible, and how to apply.
- Navigate Life Texas has helpful information. Visit their website at: https://www.navigatelifetexas.org/en/insurance-financial-help/ssi-benefits-for=childrenwith-disabilities

Who can get SSI?

- If your child is getting SSI before 18 years old, the SSA must review their medicalcondition when they turn 18 to see if they qualify as an adult.
- The rules to qualify for SSI as an adult are different than the rules for children.
 - o Before age 18, benefits are based on the family income and assets.
 - o After 18, benefits may be based only on the income on the applicant.
 - The SSA uses different medical and non-medical rules, which include a focus on the ability to work, when they decide if an adult can get SSI.

How to get SSI?

- Call the Social Security Administration at 1-800-772-1213 to make an appointment.
 - o If you are deaf or hard-of-hearing, call the TTY number at 1-800-325-0778.
 - If your illness makes it hard for you to go in-person to the Social Security Administration Office, you can ask for an interview on the phone.
- To find your local Social Security Administration office, visit https://www.ssa.gov/locator/
- To apply online, visit https://www.ssa.gov/applyfordisability/

What do I need to know?

- Fill-out the needed forms.
- When you apply for SSI, make sure to list every healthcare provider that has seen the applicant like, Doctors, Nurse Practitioners (NP), Physician Assistants (PA's), and Physical, Occupational or Speech Therapists. List them even if they only saw the applicant 1 time.
 - SSA will mail letters to these health care providers and request medical records and more information about the applicant.



- If the appointment is over the phone:
 - Be ready and by your phone 1 hour before and after the appointment time the SSA gives you.
 - Write down the name of your SSA case worker, their phone number & fax number.

What if SSI is denied?

- If the applicant gets a denial for Supplemental Security Income (SSI), you can appeal (a request to review a decision or a grievance) by phone, online or by taking the denial letter in person to any Social Security Administration Office.
- It is important to act quickly once a denial is received.
- Read the denial letter and appeal instrucions, as they will include a timeline for making an appeal.
- There are groups that may be able to help with denials of SSI. Here are a couple groups which may be a good start:
 - Disability Rights Texas: https://www.disabilityrightstx.org/en/home/
 - Texas Parent-to-Parent: https://www.txp2p.org/services/services-for-parents-pathway-to-adulthood



Adaptive Sports for Children and Teens

YMCA Dallas

Buddy Sports (basketball, soccer, field hockey, and baseball) **The Champions League** (lawn games, baseball, swimming) https://www.ymcadallas.org/adaptive special needs programs

RISE Adaptive Sports

www.riseadaptivesports.org

Special Olympics- Texas

https://www.sotx.org/

Baseball/Softball

Irving Family YMCA Miracle League

https://www.ymcadallas.org/locations/irving family ymca/sports/miracle league irving

The Miracle League of Frisco

http://www.friscomiracleleague.org/home.php

The Miracle League of Arlington

www.miracleleaguedfw.org

The Miracle League of Southlake

http://www.miracleleagueofsouthlake.com/

The Angel League (Rockwall)

www.angelleague.org

Buddy League (Garland)

www.buddyleague.org

McKinney Magic

www.mckinneymagic.org

Soccer

YMCA Dallas Buddy Sports

https://www.ymcadallas.org/adaptive special needs programs

Coppell TOPS Soccer League

http://coppellyouthsoccer.com/

Basketball

Dallas Jr. Wheelchair Mavericks Basketball

https://www.dallasjuniorwheelchairmavericks.org/

Tennis

Dallas Wheelchair Tennis Club

www.dwtc.org

ACEing Autism

https://aceingautism.org/locations/dallas-tx/





Martial Arts
Red Tiger Karate
www.redtigerkarate.com
Keller Martial Arts
www.kellerata.com

Sled Hockey
Dallas Sled Stars
http://dallassledstars.com



Respite Care Resources

Local churches in the community offer what is often called "respite care" for families of children with special needs. The churches most often offer:

- A choice of Friday night or Saturday for parents to bring their child with special needs and their siblings (under a certain age) to their church.
- During this time, there are supervised events and playtime, so that parents can enjoy a few hours without their children.
- The rooms are often split based on the level of need, and there are other events and playtime for the siblings.
- For children who have complex medical needs, there may be registered nurses (RN) to help care for them.
- Each church is different so you will have to call them for more details.

Below is a list of good places to start looking for respite care:

Friday NITE Friends, Custer Road United Methodist Church

Friday evenings; for children with special needs & their siblings www.fridaynitefriends.org
972-618-3450 ext. 247
6601Custer Road
Plano, TX 75023

Rays of Light at Lovers Lane United Methodist Church

First, second, & third Friday of each month; for children with special needs & their siblings https://www.raysoflightdallas.org/programs

214-706-9579 9200 Inwood Lane Dallas, TX 75220

Night OWLS (Out with Loving Sitters), Highland Park United Methodist Church

Second Friday of each month; for children 0-13 with special needs & their siblings www.hpumc.org (Under "Impact", go to "Belong Disability Ministry" go to "Night OWLS") e-mail: irwinl@hpumc.org (Liz Irwin)

214-521-3111

3300 Mockingbird Lane

Dallas, TX 75205

First United Methodist Church of Arlington

First Fridays of the month; for children with special needs & their siblings www.ArlingtonMethodist.org (Under "Connect", Go to "Special Needs")

e-mail: klancaster@arlingtonmethodist.org

817-274-2571 (Kay Lancaster)

313 North Center Street



Arlington, TX 76011

First United Methodist Church of Allen

For children & their siblings www.fumcallen.org (Under "Connect", go to "Special Needs Ministry" e-mail: communications @fumcallen.org 972-727-8261 601 South Greenville Ave Allen, TX 75002

Stonebriar Community Church

For children with special needs & their siblings www.stonebriar.org (Under "Ministries", go to "Special Needs") email: darlah@stonebriar.org (Darla Hill) 469-252-5200 or 469-252-5358 4801 Legendary Drive Frisco, TX 75034

Holy Covenant United Methodist Church

2nd Sat. of each month; for children with special needs & their siblings www.hcumc.org (Under "Service", "Outreach", and "Special Needs") (972) 492-2432 1901 East Peters Colony Road Carrollton, TX 75007

REVIVE, Northwood Baptist Church Keller

For children with special needs & their siblings www.northwoodchurch.org (Under "Ministries", go to "multi-ability") 817-656-8150 1870 Rufe Snow Drive Keller, TX 76248

Arise Special Needs Ministry at Irving Bible Church

Once a month on Saturday; for children with special needs & their siblings www.arisespecialneeds.com/arise
e-mail: spugh@irvingbible.org (Shannon Pugh)
972-560-4600
2435 Kinwest Parkway
Irving, TX 75063



Attendant Care Services

What is Attendant Care Services?

- In the State of Texas, Attendant Care is also called **Community Attendant Services** (CAS).
 - CAS is a medical related personal attendant care service that can help adults and children with activities of daily living (ADL's) and instrumental activities of daily living (IADL's).
 - o CAS services are provided by attendants, but they do not have a medical license.
 - You may also hear people call attendant care "respite care". The terms are alike, but respite care is focused on children in Waiver Programs that offer care given by an attendant or a nurse for a few hours a day.

Who can get Attendant Care services?

- Must be receiving Medicaid benefits.
- It is available to eligible adults and children whose health problems cause them to be limited in doing ADL's and IADL's.
 - Examples of ADLs: bathing, eating, help with going to the bathroom, dressing, and help with walking.
 - o Examples of IADLs: laundry, light housework, and making meals.
- Have a long-term disability, physical or mental health issue that has been confirmed by a doctor.
- Needing help with ADLs and IADLs based on the practitioner's statement of medical need to give their approval for these services.

What programs are available for Attendant Care Services?

Personal Care Services (PCS)

- PCS is a Medicaid service that helps people with ADL's and IADL'S.
- Your Medicaid insurance plan or your waiver will assess what level of assistance is needed.
- Children age 20 and younger and have an active Medicaid plan.
- Guardian cannot help with ADL's and IADL's.
- PCS does not involve:
 - Help with activities that a child of the same age could not do without adult supervision.
 - Respite care, childcare, monitoring, supervision, or restraint (holding of the child so they do not hurt themselves or others.)



- For more information questions about PCS, contact your Service Coordinator (SC), Case Manager (CM) or Texas Medicaid & Healthcare Partnership (TMHP)
 PCS Client Line at 888-276-0702.
- For those in a waiver program, call your Waiver SC or CM.

Personal Assistance Services (PAS)

- Services are similar to PCS.
- PAS is a Medicaid service provided by STAR+PLUS Home and Community Based Services (HCBS) waiver program.
- Adult age 21 and older with an active STAR+PLUS plan and on a HCBS waiver program.
- For more information call your Waiver SC or CM.

Community First Choice (CFC)

- Services are like PCS and PAS. CFC helps people with everyday tasks (ADLs and IADLS).
- CFC offers an additional option for habilitation services which helps teach self-care.
- Children age 20 and younger and have an active Medicaid plan.
- Must complete an assessment (in-person visit and forms to fill out) to see if your child is eligible.
- Your child must also have a certain level of medical need to get CFC services.
- For more information, or for questions regarding CFC, STAR Kids Members can call their (Managed Care Organization) MCO SC.
- For those in a waiver, call your Waiver SC or CM.

For more information on Attendant Care Services visit the websites below:

- <a href="https://www.hhs.texas.gov/services/health/medicaid-chip/medic
- https://www.navigatelifetexas.org/en/family-support/personal-attendant-care



Day Habilitation

Day habilitation programs are for children and adults with disabilities who want to learn independent living skills, enjoy activities and outings, and socialize with peers. Day habilitation programs can help individuals reach their goals of becoming as independent as possible.

What does day habilitation programs offer?

- Functional Living Skills (such as: communication, choice-making, safety, self-care, leisure and recreation, and vocational skills)
- Daily Living Skills (such as: making a bed, doing laundry, taking medicine, and hygiene)
- Social Skills (such as: conversation, making friends, and expressing emotions)
- Before and After School Care

What do I need to know about day habilitation programs?

When choosing a day habilitation program, it helps to get organized and ask the following questions:

- What is the daily cost? Although Medicaid covers most programs, ask about grants, sliding fee scales and other payment options.
- Is transportation included or available at an additional cost?
- What is the staff to participant ratio?
- Is the location convenient and the hours of operation appropriate for you and your family situation?
- · Are there any extra fees for meals or activities such as, trips, or crafts?
- What are the staff's credentials, backgrounds, and experiences? What medical professionals are available?

Ability Connection

Ability Connection's programs range from living assistance and support, to residential services and life-changing training. Within those programs, we help individuals optimize their health and fitness; social, academic and life skills; use of helpful technologies; self- expression through hands-on recreational activities, and much more.

https://abilityconnection.org/ 8802 7880 Bent Branch Drive, Suite 150 Irving, TX 75063 214-351-2500



Achievement Center of Texas

At Achievement Center of Texas, students have individual service plans which include Day Habilitation goals. Teachers work with students on these goals as well as others to give the students every opportunity to become as independent as possible. Students move from one classroom to another to train in the various skills provided by the teachers.

https://achievementcenteroftexas.org/ 302/306 N. Barnes Drive Garland, TX 75042 (972) 414-7700

My Possibilities

My possibilities is a full day, full year continuing education and job placement program, aimed to give adults with intellectual and developmental disabilities the chance at a higher education.

https://mypossibilities.org/ 3601 Mapleshade Lane Plano, TX 75075 469-241-9100

Community Homes for Adults (CHAI) Dallas

CHAI offers a group program five days a week where participants can have the opportunity to fill their day with activities and socialization to learn skills to increase their independence.

https://chaidallas.org/ 11615 Forest Central Drive, Suite 100 Dallas, TX 75243 214-373-8600

Special Abilities of North Texas

Each student will have an individual program plan with set goals in each of the five program pillars: academics/continuing education, pre-vocational and vocational training, health/nutrition/fitness, community inclusion and social development, and home and independent living skills.

https://specialabilities.net/ 1511 FM 407/Justin Road, Suite B Lewisville, TX 75077 972-317-1515

Aspire Day Habilitation

Aspire's services offered members the opportunity to socialize, enjoy peer support, and have health and social needs met in a stimulating and supportive environment that



promotes better physical and mental health.

https://aspiredayhab.com/
Lewisville-1305 South State Highway 121, Building A, Suite 160; 972-221-7888

Celina- 200 North New Mexico Street

972-382-1124

Connecting Point of Park Cities (CPPC)

CPPC is an all-inclusive, nurturing, and stimulating full or part day program for adults with disabilities. CPPC offers a wide range of educational, vocational, social, and recreational services partnering with local education agencies and recreational centers.

https://www.mycppc.org/ 4024 Caruth Drive Dallas, TX 75225 972-773-9937

HEROES Academy

Created for those who have completed secondary education and are transitioning to adulthood. HEROES Academy is a full-time program devoted to helping young adults realize their potential and gain confidential in their independence.

https://heroesdfw.org/ 101 South Coit Road, suite 36-348 Richardson, TX 75080 469-750-0022

Breckenridge Village

The Day Program at Breckenridge Village offers multiple opportunities for personal growth and continuous development. Through routine daily activities and optional enrichment activities, individuals participate in such varied experiences.

https://breckenridgevillage.com/day-program/

15062 CR 1145 Tyler, TX 75704 903-596-8100

You may also contact your local LIDDA (local intellectual and developmental disability authorities) for additional resources. https://apps.hhs.texas.gov/contact/la.cfm





What is Special Education?

Special Education is a service provided by school districts for children who have any of the thirteen qualifying disabilities that impact a child's learning process.

https://www.understood.org/en/schoollearning/ special-services/special-education basics/conditions-covered-under-idea Special education is a program funded by the federal government under the Individuals with disabilities education act (IDEA). Students can receive these services from birth-21years old. These services must be provided in the general education setting (least restrictive environment-LRE) to the extent possible. In order to receive special education services a child must qualify based on a formal evaluation given by your child's school.

How can special education services benefit my child?

Children in this program receive an individualized education plan (IEP). An IEP is a plan that is created with your child's unique learning needs in mind. IEPs ensure that students have access to regular education services on their level with necessary support in, as well as, outside of the classroom. Special Education also allows any necessary modifications, accommodations and related services your child may need. All services provided must be needed for your child to be successful at school academically or participate in activities with their peers.

How do I request special education services for my child?

- Put your concerns about your child in writing and ask the school to formally test your child.
- 2. A team of people from your child's school will meet (teacher, administrator, counselor and special education representative) to review your request.

Timeline for Special Education Services after the Request is Made:

- 15 school days after your request is put in writing the school must deny testing or get your consent as a parent to move forward with testing
- 45 school days after getting your permission to test the school has to complete the testing
- 30 calendar days after completing the testing the school must have an annual review or dismissal meeting (ARD) to share the results of the testing and develop an individualized education plan (IEP) for your child
- Services decided on for you child will take place immediately after the IEP is signed.



Example Accommodations, Modifications and Related Services:

Accommodations

Accommodations give your child access to the curriculum on grade level and ensure that your child can participate in school activities with their same age peers. Accommodations can be in a 504 plan or in your child's individual education plan (IEP).

Types of Accommodations Accessibility

- Water Breaks
- Snacks
- Wearing

Behavior

- Seat near teacher Coping strategies
- Breaks
- Calm/cool down space
- Behavior contract chart

Accessibility

- Bathroom pass
- Elevator pass
- Extra set of books at home
- Increase independence (navigating school building)

Modifications

Modifications allow for your child to work on curriculum off grade level. If your child receives modification to their work, they will have a goal to meet and a plan to meet the goal set for them in that subject area. Student's may only need modification in 1 class but can receive them in all classes. Modifications to course work are in your child's individual education plan (IEP).

Types of Modifications Reading /language Arts

- Comprehension vocabulary
- Fluency
- Finding details

Math

- Fact fluency
- Address subject areas (Algebra, Geometry)
- Measurement

Behavioral

- Decreasing outburst
- Task completion

Related Services

Related services are additional supports provided by the school to help your child be successful in the classroom.



Types of Related Services Speech and Language Services

- Letter pronunciation
- Expressive language
- Receptive language
- Communication device

Occupational/ Physical Therapy

- Handwriting
- Use of technology for written communication
- Sensory

Other Services

- Orientation and mobility for visual impaired
- Autism addendum
- Counseling

What if I disagree with the schools findings

- 1. Place your disagreement in writing.
- 2. You may check disagree on the box at your child's IEP meeting, also known as the annual, review, and dismal meeting or ARD.

For more information on disagreement process, you may review the Procedural Safeguard booklet for parents. https://www.spedtex.org/index.cfm/parent-resources/procedural-safeguards/

For More information on the special education process review the following resources: SpedTex, Special Education Information Center https://www.spedtex.org/

Texas Project First, Families, Information, Resources, Support and Training https://www.texasprojectfirst.org/

Texas Education Agency https://tea.texas.gov/academics/special-student-populations/special-education

If your child is a patient at Children's Health, you may contact the School Services Department.

School Services Department

Children's Health Children's Medical Center

Dallas Campus: 214-456-7733 Plano Campus: 469-303-4670



What is a Transitional Assessment?

What is a transitional assessment?

A transitional assessment is done by an occupational therapist (OT) trained in transitioning to adult care. You and your teen or young adult will talk to the OT about planning for your teen's or young adult's future with your teen's or young adult's strengths, needs, and interests in mind. The OT will offer ways to stay engaged in the home and community.

What ask for a transitional assessment?

During the transitional assessment, the OT will talk about skills needed to help you and your teen or young adult become confident as they move into adulthood. The OT will help you and your teen or young adult set goals and problem-solve ways to reach those goals. The OT will recommend resources for work, driving, and adult community support.

Who should take part in the transitional assessment?

Any adolescent between 14 to 20 years of age and their parent or caregiver should take part in the transitional assessment.

Where is the transitional assessment done?

The assessment can be done in-person at a Children's Health Rehabilitation Specialty Center or virtually if needed.

How to schedule a transitional assessment?

You need a referral to schedule a transitional assessment. Ask your primary care doctor or your health care team at Children's Health to send a referral to Children's Health Rehabilitation Specialty Center to complete the transitional assessment.

Does health insurance pay for a transitional assessment?

Most health insurance plans will pay for a transitional assessment. Since an OT does the transitional assessment, please ask your health insurance plan if they pay for an OT assessment



How to Get a Driver's License with Adaptations

Teens and young adults with a health condition or disability may be able to get a driver's license with adaptations. How to get a driver's license depends on the county you live in.

What is a driver's license with adaptations?

A driver's license with adaptions gives people with a health condition or disability a way to drive safely with adaptive equipment. Adaptive equipment may include lifts or ramps for wheelchairs, easy-to-use doors or handles, or changing brake and gas pedals.

How to get a driver's license with adaptations.

- 1. A doctor will decide if a patient can drive. The doctor will look at the patient's:
 - a. Health
 - b. Ability to use limbs
 - c. Motor skills
 - d. Any current injuries
 - e. Vision
- 2. Set an appointment with a driver rehabilitation specialist for an adaptive driving evaluation. A driver rehabilitation specialist will help decide which adaptive equipment is best to help the patient drive safely. To find a certified driver rehabilitation specialist visit https://www.aded.net/page/725.
- 3. Find a driver's education training program that teaches how to operate a vehicle using adaptive equipment. To find a course visit https://www.aded.net/.

Steps to get a driver's license if you are under 18 years old

- 1. Apply for a learner's license.
 - a. You must finish the first 6 hours of a driver's education course before applying for a learner's license.
 - b. You must have a learner's license for 6 months before applying for a driver's license.
 - c. Teens or young adults must finish a certain number of driving hours. Driving hours can be done through a driving education program or with a parent or caregiver.
- 2. Apply for a driver's license. To apply for a driver's license, you must
 - a. Be at least 16 years old.
 - b. Finish all 32 hours of a driver's education program.
 - c. Pass a written test.
 - d. Pass a driving test.
 - e. Pass an eye exam.
 - f. Have enough driving hours with a learner's license.



Steps to get a driver's license if you are over 18 years old

- 1. Complete the Impact Texas Adult Drivers (ITAD) program online. https://www.dps.texas.gov/section/driver-license/impact-texas-drivers-itd-program
- 2. Complete a 6-hour adult driver education course.
- 3. Apply for a driver's license.

Testing accommodations

You can ask for testing accommodations (changes to help you take a test). Fill out the online form on the Texas Department of Public Safety website to ask for accommodations. https://www.dps.texas.gov/apps/DriverLicense/customer_service/ADA.aspx.

Accommodations may include:

- extra time for testing,
- a private room,
- having test questions
- read out load, and breaks.

More resources to help teens and young adults

- For more information on driving and ride options for teens and young adults with disabilities and special health care needs,
 visit: https://www.navigatelifetexas.org/en/transition-to-adulthood/driving-and-transportation-options-for-young-adults-with-disabilities.
- The Texas Department of Public Safety can add a communication impediment indicator to a driver's license or identification (ID) card to help police understand your teen or young adult during traffic stops. Find more information at https://www.dps.texas.gov/section/driver-license/communication-impediment-peace-officer.



Vocational Rehabilitation Program

Through the Texas Workforce Commission (TWC), the Vocational Rehabilitation Program helps teen and adults with disabilities get ready for work or college. These services offer work training, work counseling, hearing aids, transportation, sign language interpreters, on-the-job support, and more.

What Type of Services are Offered?

Youth & Student Services can help with either preparing for college or help finding a job. To get services, you must:

- Be between ages 14-22
- Live in Texas
- Be preparing for work or college
- Need help finding or keeping a job
- Have a health issue that affects your ability to work such as:
 - o Behavioral and mental health conditions
 - Hearing impairments
 - Alcoholism or drug addiction
 - Intellectual disability
 - o Learning and developmental disabilities
 - Physical disabilities like brain or spinal cord injury
 - Vision-related disabilities like blindness

To learn more, visit https://www.twc.texas.gov/programs/vocational-rehabilitation/youth-students.

How to Apply for Services?

To apply for services:

- Contact your nearest Texas Workforce Solutions Vocational Rehabilitation Services, find your nearest Vocational Rehabilitation Office at https://webp.twc.sate.tx.us/services/VRLookup/
- Call 512-936-6400 or Email <u>vr.office.locator@twc.texas.gov</u>. In your email include your name, phone number, and full address. Do **not** include your Social Security Number or birthdate.

Application Process

Contact your local Vocational Rehabilitation Office.

• Schedule a meeting with a staff member for services and to complete paperwork.



If you are eligible:

- Work with your vocational rehabilitation counselor to develop an Individualized Plan for Employment (IEP) within 90 days. This plan includes your employment goal and approved services.
- You will then receive training and services from your counselor or a provider.

Adult Services can help you prepare for work, look for work, keep current job, or advance in current job.

To get services, you must:

- Live in Texas
- Have a health issue that affects your ability to work such as:
 - Vision loss, deafblind, or blindness disabilities
 - Psychological or mental health disabilities
 - Deaf or hearing loss
 - Addictions with alcohol or substance use
 - o Intellectual, dyslexia or other learning difficulties
 - Neurodevelopmental disorders such as autism and ADHD
 - Physical disabilities that include traumatic brain injury (TBI) or spinal cord injury
 - Arthritis and other related issues
 - Other physical disabilities that involve individuals who feel pain while moving around
- Be looking for a job, wanting to keep a job or wanting to advance in current job To learn more, visit https://www.twc.texas.gov/programs/vocational-rehabilitation/adults.

How to Apply for Services?

To apply for services:

- Complete an online referral form at https://www.twc.texas.gov/programs/vocational-rehabilitation/adults
- Contact your nearest Texas Workforce Solutions Vocational Rehabilitation Services, find your nearest Vocational Rehabilitation Office at https://www.twc.texas.gov/find-locations
- Call 512-936-6400 or
- Email vr.office.locator@twc.texas.gov. In your email include your name, phone number, and full address (city & zip code needed)
- After completing the online referral, a staff member will contact you.

Application Process

Contact your local Vocational Rehabilitation Office.



- Turn in an application by mail or schedule a meeting either online or in-person with a staff member for services.
- You will be contacted by SARA (Semi-autonomous Research Assistant) a software used to help with communication, either before or after your application is completed.
 - You will receive a text message from number 34459 or email with "SARA Introduction"
- The TWC vocational rehabilitation counselor will contact you within 60 days.

If you are eligible:

- You will complete vocational and other assessments.
- Work with your vocational rehabilitation counselor to develop an Individualized Plan for Employment (IEP) within 90 days. This plan includes your employment goal and approved services.
- You will then receive training and services from your counselor.

To learn more, visit the TWC Vocational Rehabilitation Inquiry website: https://webp.twc.state.tx.us/services/VRLookup/





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