



skills.

ROADMAP

FOR

Transitioning to Adult Healthcare Services exciting and overwhelming experience. A roadmap can be helpful, but there are many roads to adulthood and each family will travel the roads best fit for them. Health care

transitions serve as a bridge between the pediatric and adult healthcare settings and is tailored to the individual's social.

The best way to get started is by including your child in the process and helping them to find their voice in their own

physical, emotional, and functional needs.

health care. Allow them room to practice managing taking care of themselves, knowing their medications, setting up appointments and even filling out forms.

Now is the time to support your child setting goals, help them to build the skills to be able to make choices, encourage them to ask questions and be able to speak up for their needs. It can be complicated and not a quick process to develop self-reliance, self-confidence and self-management

However, together you and your child can discuss what is meaningful to them and knowing that can help determine the what's best next step for them. As they learn more about themselves allow them to dream big and strive to become the directors of their care.

Got Transition has a good Health Care Transition
Timeline for Parents/Caregivers in English and in En
Español. Plus it has a Health Care Transition Timeline for
Youth and Young Adults and in En Español.

Health Care Transition Timeline



for Parents/Caregivers

Age 12-1

- Help your teen learn about their own health condition, medications, and allergies.
- Encourage your teen to ask their doctor questions about their own health.
 Ask your teen's doctor if and at what age they no longer care for young adults.

ge 14-15

- Learn what your teen knows about their own health, health care, and family medical history.
 Both you and your teen can take Got Transition's Transition Readiness Assessments* and discuss this together and with the doctor.
- Have your teen carry their own health insurance card.
- · Help your teen learn more about their own health and what to do in case of an emergency.
- Help your teen practice making a doctor's appointment and ordering prescription refills (either by phone, online, or through an app).
- Encourage your teen to see the doctor alone for part of the doctor's visit to help gain independence in managing their own health and health care.

ge 16-17

- Encourage your teen to make doctor's appointments, see the doctor alone, ask the doctor questions they may have, and refill medications.
- Ask the doctor to talk with your teen about their privacy rights when they turn 18.
- Work with your teen and the doctor to make and share a medical summary.
- Before your teen turns 18 and becomes a legal adult, figure out if they will need help making health care decisions. If so, ask your Family Voices chapter for local resources.
- Talk with your teen about the age they want to transfer to a new doctor for adult care.

Age 18-21

- At age 18, your child is a legal adult and legally responsible for their care. You cannot access
 their medical information or be in the doctor's visit unless your young adult agrees or certain
 legal forms have been completed.
 - · If you need local resources on supported decision-making, ask your Family Voices chapter.
 - Learn if there are additional changes at 18 that affect your young adult (e.g., health insurance, Social Security Income).
 - Encourage your young adult to ask their current doctor to find a new adult doctor. Make sure
 that the new doctor accepts your young adult's health insurance, and help them learn if there
 are any charges at the visit.
- Encourage your young adult to keep a copy of their medical summary and always carry their health insurance information with them.

Age 22-2

- Encourage your young adult to get care from their adult doctor, learn to manage their own health and health care, and update their medical summary.
- Encourage your young adult to stay insured. If they change health insurance, encourage them
 to make sure their doctor takes their insurance and learn if there are any charges at the visit.

*For a Transition Readiness Assessment for youth, visit https://gottransition.org/6ce/leaving-readiness-assessment-youth and for a version for parents/caregivers, visit https://gottransition.org/6ce/leaving-readiness-assessment-parent.

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Health Care Transition Timeline

for Youth and Young Adults

Age 12-13

- · Learn about your health condition, medications, and allergies.
- · Ask your doctor questions about your health.
- Ask your doctor if and at what age they no longer care for young adults

Age 14-15

- Find out what you know about your health, health care, and family medical history. Both you
 and your parent/caregiver can take Got Transition's Transition Readiness Assessments* and
 discuss this together and with the doctor.
- · Carry your own health insurance card.
- Learn more about your health and what to do in case of an emergency.
- Practice making a doctor's appointment and ordering prescription refills (either by phone, online, or through an app).
- Begin to see the doctor alone for part of the doctor's visit to help gain independence in managing your health and health care.

ge 16-1

- Make doctor's appointments, see the doctor alone, ask the doctor any questions you have, and refill medications.
- Ask the doctor to talk with you about your privacy rights when you turn 18.
- Work with your doctor to make a medical summary. Keep a copy for yourself.
- Before you turn 18 and become a legal adult, figure out if you will need help making health care
 decisions. If so, ask your Family Voices chapter for local resources.
- Talk with your parent/caregiver about the age you want to transfer to a new doctor for adult care.

Age 18-21

- You are a legal adult at age 18 and are legally responsible for your care. Parents/caregivers
 cannot access your medical information or be in the doctor's visit unless you agree.
- Work with your current doctor to find a new adult doctor, if needed. Make sure that the new doctor accepts your health insurance.
- Update your medical summary with your doctor. Have your doctor send this to your new adult doctor. Keep a copy for yourself.
- Call your new adult doctor to schedule the first appointment. Make sure the new office has
 your medical information, and learn if there are any charges at the visit.
- Learn if there are additional changes at 18 that affect you (e.g., health insurance, Social Security Income).

ge 22-25

- Continue to get care from your adult doctor, learn to manage your health and health care, and update your medical summary.
- Be sure to stay insured. If you change your health insurance, make sure your doctor takes your insurance, and learn if there are any charges at the visit.

*For a Transition Readiness Assessment for youth, visit https://gottransition.org/6ce/leaving-readiness-assessment-youth and for a version for parents/caregivers, visit https://gottransition.org/6ce/leaving-readiness-assessment-parent.

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How to know if you are ready to transition to adult care?

Let's Find Out!



Every person's journey is unique and the way an individual completes a daily task varies. Some people might need no assistance, others need a little or a lot and others may need to use equipment or ask other people to help with finishing a task. Knowing which daily activities require support can help a person to plan their day and gain independence. What kinds of tasks are easy, difficult and or require assistance?

Another quiz to see if your child is ready can be found here https://www.gottransition.org/youth-and-young-adults/het-quiz.cfm It is part of the go transition website that has lots of extra information to share.

Take some time to complete this form here It is a survey adapted from the Transition Readiness Questionnaire, TRAC. It asks questions regarding self-care, medication management, appointments, tracking health, talking with providers, managing daily activities and Spina Bifida related daily health occurrences. You or your child may have already filled out something similar to this with your child's pediatric provider but it's great place to get started and see if they are ready or what skills you all need to work on.



Helping your child to begin to manage their own care can begin by:

- Talking to them about how you help them with self-care. For example, explain in terms your child can
 understand why and how you help them go to the bathroom using their bowel program.
- With the self-care skills your child needs assistance, help them to learn how to ask and instruct others to help them with these tasks.
- Begin talking about a doctor's appointment /clinic appt medical procedure test prior to arriving so your child can know what to expect. It can also begin to provide your child with increased ownership of their medical care.
- Ask if them if have questions or worries about seeing the doctor. Come up with up a least one question and
 write it down so that you al can share with the doctor when at the visit. Talk about what worries them and
 encourage them to share their worries with the doctor.
- Begin to have your child help you fill out their medical forms. You can begin this by explaining that their doctor
 wants to know more about them and how they are feeling, "let's answer these questions together!"

Parts of this survey are in additions to the originally established Transition Readiness Questionnaire (TRAC). © Wood, Sawicki, Reiss, Livingood & Kraemer, 2014 Directions to Youth and Young Adults: Please check the box that best describes your skill level in the following areas that are important for transition to adult health care. There is no right or wrong answer and your answers will remain confidential and private. Directions to Caregivers/Parents: If your youth or young adult is unable to complete the tasks below on their own, please check the box that best describes your skill level. Check here if you are a parent/caregiver completing this form. Yes, I have No, I do No, but I No, but I Yes, I Not applicable always do not want to am learning started doing this know learn to do this this when N/A how I need to Self-care Do you require assistance to dress/undress your upper body? Do you require assistance to put on/off orthotics (back brace or leg braces)? Do you require assistance to dress/undress your lower body? Do you require assistance to put on/take off socks and shoes? Do you require assistance to wash/dry your upper body? Do you require assistance to wash/dry your lower body? Transfers Do you require assistance to transfer from bed to w/c? Do you require assistance to transfer from w/c to bed? Do you require assistance to transfer from w/c to car? Do you require assistance to transfer from car to w/c? Do you require assistance to transfer from w/c to shower chair or bench? Laundry/Dishes Do you require assistance to

wash/dry your clothes?

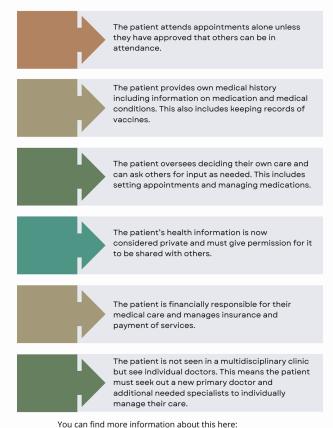
Do you require assistance to wash/dry dishes and/or use the

dishwasher?

Managing Medications				
Do you fill a prescription if you need				
to?				
Do you know what to do if you are				
having a bad reaction to your				
medications?				
Do you take medications correctly				
and on your own?				
Do you reorder medications before				
they run out?				
Appointment Keeping				
Do you call the doctor's office to				
make an appointment?				
Do you follow-up on any referral for				
tests, check-ups or labs?				
Do you arrange for your ride to				
medical appointments?				
Do you call the doctor about unusual				
changes in your health (For example:				
Allergic reactions)?				
Do you apply for health insurance if				
you lose your current coverage?				
Do you know what your health				
insurance covers?				
Do you manage your money &			ĺ	
budget household expenses (For				
example: use checking/debit card)?				
Tracking Health Issues				
Do you fill out the medical history				
form, including a list of your				
allergies?				
Do you keep a calendar or list of				
medical and other appointments?				
Do you make a list of questions				
before the doctor's visit?				
Do you get financial help with school				
or work?				
Talking with Providers				
Do you tell the doctor or nurse what				
you are feeling?				
Do you answer questions that are				
asked by the doctor, nurse, or clinic				
staff?				
Managing Daily Activities				
Do you help plan or prepare				
meals/food?				
Do you keep home/room clean or				
clean-up after meals?				
Do you use neighborhood stores and				
services (For example: Grocery stores				
1 1 1 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2				

and pharmacy stores)?

DIFFERENCES BETWEEN A PEDIATRIC MEDICAL VISIT AND AN ADULT VISIT



https://www.navigatelifetexas.org/en/transition-to-adulthood/medical-transition



It is great to have important health-related information at your fingertips and something that can be easily accessed by anyone in the event of an emergency. All that information can be stored on your phone!

Go Here for Instructions to set up Medical ID on an I Phone

• Setting up a Medical ID on an iPhone (English | Spanish)

Go Here for Instructions to set up Medical ID on an Android

• Setting up a Medical ID on an Android (English | Spanish)

Go Here to set up an Emergency sheet

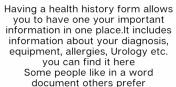
 Also go here https://disabilityrightstx.org/en/handout/emergency-readysheet/ to find a more detailed form to complete. It will allow you to print and/or save to a device important information to have with you in the case of an emergency.

Video

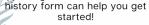
 Check out This helpful video about emergency plans from the Federal Emergency Management Agency on ways to prepare for the unexpected.

HOW CAN I ORGANIZE MY HEALTH INFORMATION

There are various ways to organize health information and what's best depends on what works for you and your family. Navigate Texas describes what kind of information is needed in a care notebook here https://www.navigatelifetexas.org/en/diagnosis-healthcare/care-notebook



spreadsheet format or even something digital. Whatever feels the most comfortable for you is the type to go with and this health



	HEALTH HISTORY				
NAME:	_DOB:				
EMERGENCY CONTACT:	PHONE NUMBER:				
INSURANCE:	GROUP/INDI				
DIAGNOSIS:	LEVEL FUNCTION:				

EQUIPMENT: WHEELCHAIR YES NO IF APPLICABLE WHAT TYPE OF CUSHION

SKIN ISSUES: HISTORY OF WOUNDS YES NO LOCATION:

_LENGTH:

BRACES: YES __ NO (TYPE: SMOS . AFOS KFOS HKSOS TLSOS)

_PHONE: .

REACTION:

_PHONE:

BLADDER MANAGEMENT: VOID VOLITIONALLY VESICOSTOMY CLEAN INTERMITTENT CATHETERIZATION CATHING: URETHRA APV CATH TYPE: STRAIGHT COUDE HYDROPHILLIC OTHER:

PROCEDURES: BLADDER AUGMENTATION APV VESICOSTOMY BOTOX BLADDER OUTLET DEFLUX URETERAL REIMPLANTATION STONE SURGERY ORCHIOPEXY ORCHIECTOMY

PAST UROLOGY FINDINGS: HYDRONEPHROSIS VESICOURETERAL REFLUX _HIGH PRESSURE ON VUD (>40 CM H20)

DOSAGE:

V. NUMBER:

FAX:

N/A

FAX:

INFECTION: YES NO

_PHONE: .

FREQUENCY: EVERY ____ HOURS

PHONE:

FREQUENCY:

_PHONE:

AMOUNT/FREQUENCY:

PHARMACY: MEDICATIONS:

ALLERGIES:

ORTHOTIST:

SIZE: VENDOR:

UROLOGIST: DR.

WALKER YES NO VENDOR:

WOUND MANAGEMENT (IF APPLICABLE)

OVERNIGHT CARE (IF APPLICABLE):

BLADDER IRRIGATION . YES NO (SOLUTION: .

BOWEL PROGRAM: ORAL MEDS			
EVACUATION: SUPPOSITORY	ENEMEEZ	NE/BALLOON ENEMA MACE/ACE	
DIGITAL SIMULATION TIME	DISIMPACTION		
ENEMA SOLUTION (IF APPLICABLE):			
FREQUENCY OF RECTAL INTERVENTION	N: DAILY (. AM	PM) EVERY OTHER DAY OTHE	R.
ORTHOPEDIC: DR.	PH	ONE:	
FOLLOW UP NEEDED: EVERY 6 MG	ONTHS YEARLY E	VERY 2 YEARS TBD	
CONDITIONS TREATED: SCOLIOSI	S KYPHOSIS HIP	CONTRACTURE HIP SUBLUXATION/	DISLOCATION
KNEE CONTRACTURE TIBAL T	ORSION FOOT DEFORMIT	CLUBFOOT	
NEUROSURGEON: DR.	PH	ONE:	
FOLLOW UP NEEDED:EVERY 6 MG	ONTHS YEARLY	EVERY 2 YEARS TBD	
PROCEDURES: FETAL CLOSURE	POSTNATAL CLOSURE	_TETHERED CORD RELEASE	RI DECOMPRESSION
SYRINX SHUNT SHUI	NT PLACEMENT SHUNT	PROGRAMMABLE:	YES NO
OTHER SPECIALISTS:			
DR.	. PHONE:		
DR.	PHONE:		
DR.	PHONE:		
OTHER SURGERIES NOT LISTED ABOVE	:		
ТҮРЕ:	DATE:	SURGEON:	
TYPE:	DATE:	_ SURGEON:	,
TYPE:	. DATE: _	SURGEON:	
TYPE:	DATE: _	SURGEON: _ SURGEON:	

Did you know.... There's an app for that?

The National Spina Bifida association has created an app that helps you share information about your health with your physician.

Check it out here to https://www.spinabifidaassociation.org/mobile-application/

The app has links to the guideline of care so that you have it on hand at any appointment. It also provides the user with a centralized location to track an individual's health symptoms including but not limited to: skin integrity, physical activity, pain, problems with sleep, medications, bowel management plans, catheter routines, and a note section.

Instructions for an Apple I phone

Go here to find instructions on how to load to the phone (English | Spanish)



Instructions for an Android phone

Go here to find instructions on how to load to the phone (English | Spanish)



How to find the best medical team for adulthood



After leaving pediatric care, finding a primary care physician and other specialists can be a daunting and involved process. Often, we seek recommendations from friends, family, neighbors and even our social media network, but in the end, it is still up to you in deciding what is the best fit for your family's needs and situation. If your child has Medicaid, their service coordinator can assist with finding an adult provider who accepts their insurance.



Here are some questions that can begin to help you find a physician right for you



Telling a new doctor about all the things that make you unique is an invaluable part of advocating for and establishing a good healthcare partnership. Here is a template that can help share all the important things about who you are with a new physician and don't forget to also share your health history form found here.

Feel free to print it out and bring it with you to your appoinments

HOW TO FIND THE RIGHT PHYSICIAN FOR YOU

Questions to ask when searching for a new provider

Insurance	Do they take your insurance. To verify if your choice doctor is in network. A good place to start is the health plan's website. Most health plans have a "find a doctor" search tool. Search for your doctor there and see if they show up as in network (or preferred or Tier I) or out of network. You can also call your doctor's office directly and ask if your doctor participates in the health plan. They will be able to tell you if the doctor and facility are fully or partially covered.
Location	Is the doctor located close to you? Does the doctor see patients at multiple locations? What hospital system do they have privileges to see patients?
Communication	How does the doctor communicate with their patients? Do they speak your/your family's language? Does the doctor use email or an online portal? How will the doctor exchange information with your specialists?
Availability	What are the office hours? Does the doctor have an after-hour care option? Does this doctor have a telemedicine appt option. How far in advance do you need to make an appointment?

Questions to ask when searching for a new provider

Centralized Care	Does doctor have an onsite lab and testing at the main office location, or do you have to go somewhere else?
Accessibility	Does the building, waiting room, patient room and lab testing area meet your accessibility needs?
Referrals	Has this doctor seen anyone you know? Has this doctor had/have helped patients that were born with Spina Bifida. Look for other patient reviews! Is the doctor Board Certified?
Visit the Doctor	Evaluate the office staff and how they treat the others in the waiting room. How long is the wait to see the doctor after you arrive for your appointment? Do you feel as though you and the doctor are on the same page with managing your care?

My name is

My goal is to have a doctor that knows me and will be able to communicate with me, those that support me and my other specialists to provide me with the best possible quality of care. Here are more things you need to know about me.

About me	
I'm from:	
I now live in	and live with
My family includes:	
I attended	school
A typical day for	
me looks like	
Things I value	
and find	
important	
Things that	
interest me	
Things that I	
would like to	
do but have	
difficulty with	

Things that worry me	
Things that	
and bad habits	
Ot	her important details

check all that apply

- I like to take notes during the doctor's appointment
- I like to have a print out of what we discuss at the appointment
- I prefer my parent/ friend/caregiver to be present during my appointment
- I like to bring my written questions/concerns to the appointment



VOCATIONAL REHAB SERVICES





There are many roads after high school and identifying what things interests your child can be a good place to start when deciding between work, volunteering, vocational programs, trade school, 2 year college or 4 year university.



Depending on the educational setting, your child may be eligible to stay in school until the age of 22, even after graduating. Reach out to your school's special education department for more information and assistance with planning your child's transition from school services. You can also reach out to the PACT Project at 1-855-974-1368 for help advocating for your child.

TRADE SCHOOL

With the help of a rehabilitation counselor your stude can also explore if they are in interested in a pursuin, trade job. Trade jobs can vary from aircraft mechanic cooks, electricians, heating and air conditioning mechanics to cosmetology. Go here to find out more about trade jobs and schools located here in Texas https://www.bestcolleges.com/united-states/texas/trade-schools/ It provides information o average cost, location, accreditation, admission and graduation requirements.

TEXAS WORKFORCE COMMISSION VOC REHAB (TWC-VR)

It supports people with disabilities to prepare for, obtain, maintain and advance in meaningful employment or education by providing a range of services based on an individual's employment goals. More information can be located here https://www.twc.texas.gov/ and here is the information for your local office if you are interested in services

Vocational Rehabilitation Services

1919 S. Shiloh Rd. Garland, TX 75042 214-778-4930

THE TEXAS EDUCATION



The TEA Has an in-depth education transition planning for education and employment guide located here

https://tea.texas.gov/academics/special-studentpopulations/special-education/programs-andservices/state-guidance/secondary-transitionguidance

PRE EMPLOYMENT TRANSITION SERVICES THRU TWC-VR

- · Job exploration counseling
- Work-based learning experiences, which may include in-school or after school opportunities, experiences outside of the traditional school setting, and/or internships
- Counseling on opportunities for enrollment in comprehensive transition or postsecondary educational programs
- Workplace readiness training to develop social skills and independent living
- · Instruction in self-advocacy

Go here for more info and a link for a self referral https://f2fn.org/getting-started/resources/employmentsupports/

College



Important first step in preparing for college is the student become a participant in the decision process and starts attending their IEP/504 meetings. Talking about it early, in high school, can help with developing a plan and ease anxiety. Begin with identifying interests, things of value, things that the student is passionate about and their current abilities. and go on in person college tours. It is never too early to start; the sooner can help ease anxiety and help identify life skills needed for college life.

When looking for the **right fit** college, start with these questions to help you know more about the college you are researching. Remember to compare what you need and what they offer.

College Readiness skills

Knowing your college readiness and understanding what to expect in college can help.

The following are some expectations of your new role as a college student.

- 1. Academic level: quality and quantity of work is much greater than high school.
 - Difficult study skills, note taking and the degree of homework is larger
- Structure: many hours of unstructured time in college- Go from a very structured day to only in class a couple hours a day and you will need time management, organization and focusing.
- 3. Self Advocacy: is very key! need to understand rights and school policies; ask for and use support.
- 4. Independent living skills: can be challenging. dorm, personal hygiene, food, money transportation
- 5. Social skills: able to initiate plan follow through
- 6. Role and involvement of parents: student is the lead; student send their own emails. much greater level of independence

that you are interested in?	What size town is the campus located in? Is there public transportation? How will you move about the city/town?
Admission Requirements	Cost
Do they have activities, sports, theatre, and service/volunteer or social/religious clubs that you are interested in?	Is it located out of state- will need to pay out of state tuition and travel costs every time you need to come home. Will you need financial aide? Will you need to work?
Involvement on Campus	Size of Classes
Do they have activities, sports, theatre, and service/volunteer or social/religious clubs that you are interested in?	What is the student to teacher ratio? lecture hall vs lab classroom

Location

• How far away from home is the school?

Will it be difficult to come home when

needed?

Area of Interest

Does the college offer courses

and have a major in the topics

that you are interested in?

Housing

- What are the housing requirements-do you have to live on campus?
- What does it really look like living on a campus?
 Do they have single room and private bathroom dorm options?
 - Is the dorm building, personal room, bathroom, shower, and closet accessible to you based on your mobility needs?

Campus Suppo

· Academics-Do they offer tutoring,

hall and the common areas.

daily self needs?

- Campus Supports What accommodations are available?
- writing support or academic coaching?
 How are the classes offered? -Lecture hall and lab setting

 Transportation: Does this campus offer Buses/shuttles?

 Is handicap parking at a functional
- Housing: Can this college meet you accommodation needs for residence

 Housing: Can this college meet you accommodation needs for residence
 - best help getting around campus and the surrounding college town?

 Will a wheelchair or scooter be needed? (You may have been not
- Dining: Does this campus have a cafeteria? Is the student responsible for cooking?

 Programs: Are all school sponsored campus

 Outputs (Sports smallers etc)

 Outputs (Sports smallers etc)
 - events (Sports, speakers, etc)
 accessible? Does the college have a first
 year experience/Orientation?

 Independent living skills: Does the
 school offer personal care assistant
 services to assist with the student's

 Continuity of Care: How do you manage
 doctor visits if away from home?

 What information should share
 with campus physician if need to
 see them?

 How to manage medication and
 set up new access to a pharmacy
 for renewal of prescriptions?

AFTER COLLEGE ACCEPTANCE



Contact Disability service office on Campus

- Every college or University will have a department dedicated to disability services
 this includes helping students. It may have a different name but the main focus is
 to provide every student with assistance on needed accommodations. The office
 may also house a testing center for those students needing that type of
 accommodations.
- To be able to receive accommodations it is the student's responsibility to self-identify to disability support office.
- It is expected for the student initiate and self-advocate for accommodations with professors.
- Every college is unique, check with each college to find out what type of documentation you will need to provide.
- Documentation could include but not limited to:
- Neuropsychological evaluation (your Pediatric Developmental pediatrician will recommend this type of testing multiple times throughout K-12 for insight on how your student learns and processes information.
- Psychological Evaluation if mental condition
- Healthcare provider (Letter diagnosis, outline of functional limitations, recommendations of accommodations) -healthful for chronic conditions
- IEP's do not follow you to college, however if you feel the
 information provides an accurate description of your student it can
 be helpful to share the IEP as a supplemental information to the
 disability services office.



Wheels on Campus

The guide, funded by a grant from the Craig H. Neilsen Foundation, is available here as a free download.



INTERNSHIP OPPORTUNITIES

The Workforce Recruitment Program (WRP) "connects employers with college students and recent graduates with disabilities who are eager to demonstrate their abilities in the workplace through summer (internships) or permanent jobs."

Get access to Federal Government jobs and internships nationwide

Strengthen resume and interview skills.

Expand your knowledge of Federal Government employment, including the

Schedule A hiring authority for people with disabilities.

Explore career opportunities.

It is managed by the U.S. Department of Labor's Office of Disability Employment Policy and the U.S. Dept of Defense. You can find more information here https://www.wrp.gov/wrp?id=student_landing_page



OTHER OPPORTUNITIES

American Association of People with Disabilities (AAPD) Summer Internship Program: college students, graduate students, law students, and recent graduates with all types of disabilities in summer internships with Congressional offices, federal agencies, non-profits, and for-profit organizations in the Washington, DC area. For more information go here https://www.aapd.com/summer-internship-program/

NextGen Leaders Initiatives: NextGen Leaders are college students and recent graduates with disabilities who have demonstrated talent and leadership in the STEM, finance and business fields. For more information go here

https://disabilityin.org/what-we-do/nextgen-leaders-initiatives/apply-faq/.

Other Resources to help you while in college

Having trouble getting accommodations approved...

If you have followed your specific college's procedure to request accommodations, provided proof of your disability, and completed everything within established deadlines and are still having difficulty with getting your accommodations approved. The next step is for you to file a grievance. Disability Rights of Texas can help with free legal guidance you can contact them here https://disabilityrightstx.org/en/category/collegerights/ then click on How to Apply for Services. Disability Rights of Texas is a great advocate for when you need help with an educational situation/question.

Know your rights

The Family Educational Rights and Privacy Act (FERPA) go here for more information https://studentprivacy.ed.gov/resources/ferpa-general-guidance-parents and here https://www2.ed.gov/policy/gen/guid/fpco/ferpa/index.html As an adult your child's information, grades, tuition bills are private if you have the FERPA waived then the college can speak to a parent on these issues.

On the web

An Amazing Webinar titled College Opportunities and Success for Students with Disabilities and it can be found here https://youtu.be/eKQ4zioBm4g The two main speakers are college education consultants. Annie Tulkin from www.accessiblecollege.com she specializes in helping students with physical disabilities and chronic health conditions. The second consultant, Scot Markem from EdRedefined https://www.edredefined.com/supports students with Autism, ADHD, mental health challenges and learning differences.

On the bookshelf

Special Education to college The Ketrina Story Breaking those glass ceilings.

Ketrina has established her own nonprofit to network community mentoring for transition and beyond. The Disability Champions Project will enhance Special Education transition programming for underserved youth with disabilities and support empowerment through the development of specialized mentors to help create an authentic community of support. Find out more here: http://www.disabilitychampionsmentoringnetwork.org/

FINDING EMPLOYMENT



WANT TO BECOME A FEDERAL GOVERNMENT EMPLOYEE

According to the U.S Equal Employment Opportunity Commission, "The Schedule A Hiring Authority for people with disabilities (Schedule A) is an exception to the traditional hiring process. Schedule A streamlines the hiring process for persons with disabilities and, in some instances, hiring officials may select solely from a list of qualified Schedule A applicants. You can apply using Schedule A if you are a person with an intellectual disability, a severe physical disability, or a psychiatric disability. In order to be selected you will need to show that you meet the qualifications of the job (with or without reasonable accommodation)." Go here to learn more https://www.eeoc.gov/publications/abcsschedule-tips-applicants-disabilities-gettingfederal-jobs

TEXAS WORKFORCE COMMISSION

Provides one on one assistance:

- Vocational counseling & guidance
- Job placement assistance
- College/vocational training
- Supported employment services
- Skills training
- Job coaching/tutoring
- Transportation
- Interpreter services
- Services to transition-age youth
- Accommodations
- Assistive technology and rehabilitation technology services; referral services; support, advocacy, and follow-up services.

More information can be located here https://www.twc.texas.gov/



ONLINE JOB SITE

A large job site page for persons with disabilities is located here https://abilityjobs.com/

It is a resource that offers an online job site for persons with a disability and connects businesses, government, and non-profits to the job seeker. Plus it shares helpful articles with topics such as how much personal information should be shared, reasonable accommodations, work life balance and a culture of inclusion. It even has an online job fair!

Other helpful sites

- There's a wealth of info about jobs and "getting employed" in this resource.
- http://parentcenterhub.org/repository/employers/
- Our Ability Connect: A searchable database of job openings for people with disabilities
- Bender Consulting: Serves as a headhunter agency for companies looking to hire people with disabilities.
- Lime Connect: introduces highly accomplished individuals with disabilities to scholarships, fellowships, and careers with the world's leading corporations.
- Getting Hired: A job search engine for people with disabilities and veterans
- NTI: An agency that provides training and support for individuals interested in work at home positions.
- Think Beyond the Label: A national campaign to promote disability hiring. It also hosts virtual career fairs and a job search.



Workplace Accommodations

When needing help with workplace accommodations or have questions about ADA contact Job Accommodation Network (JAN) here at the JAN home page. It has amazing information and resource links on finding a job, disclosure, and pre-employment do's and don'ts can be found here https://askjan.org/info-by-role.cfm#for-individuals:job-seekers

Also, JAN has gathered information specifically about Spina Bifida on the home page see below: select Disabilities and Spina Bifida then GO. It will lead you to a compliance and accommodation page with more resources explicitly for Spina Bifida.



Local Centers for Independent Living provide services that assist you with advocacy, help with independent living skills training, peer counseling, and information and can refer you to other agencies. You can go here to find the agency that serves your area. First look up by state it will provide a list all of the centers state-wide. You can then filter by county or city to get a more specific list for your location.

For Dallas County:



Legal Decision Making

Deciding how much assistance your child will need in making medical, legal and life decisions can be overwhelming and often can feel very complicated. A good place to start is to seek their doctor's recommendation and go to Navigate Life Texas This website offers a large amount of information on decision making and options for families, including guardianship or supported decision making.



These websites, along with your doctor's recommendation, will be helpful in determining what type of support your child may need with making their own decisions.

Supported Decision Making

is when a person delegates a family member or friend that they trust who can help them make decisions. Decisions can include but are not limited to having assistance with obtaining food, clothing and a place to live, help with physical health, mental health, managing money or property, getting an education or other training, finding a job and choosing and maintaining my services and supports.

Disability Rights Texas

Has a good explanation of this go here to learn more about a supported decision making agreement . https://disabilityrightstx.org/en/hand out/create-a-supported-decisionmaking-agreement/

Guardianship

Guardianship of the person is when a court gives a responsible person (the guardian) full or partial decision-making power (authority) for an adult (the ward) so that the guardian can protect and look after them.Go here to learn more about guardianship https://www.navigatelifetexas.org/en/transi tion-to-adulthood/legal-quardianship-for-

young-adults-with-disabilities-1





GOVERNMENT SERVICES

SSI BENEFITS

- IF YOUR CHILD DOES NOT ALREADY RECEIVE SSI BENEFITS, THEY MAY QUALIFY ONCE THEY TURN 18. YOU CAN APPLY FOR BENEFITS ONLINE THROUGH THE SOCIAL SECURITY ADMINISTRATION OR IN PERSON OR BY PHONE CALL +1 800-772-1213 CALL TTY +1 800-325-0778 IF YOU'RE DEAF OR HARD OF HEARING. TELL THE AGENT YOU WANT TO SET UP AN APPOINTMENT TO APPLY FOR BENEFITS. THEY'LL SCHEDULE IT AND DETERMINE WHETHER IT'LL BE ON THE PHONE OR IN PERSON.
- A LIST OF MATERIALS NEEDED TO COMPLETE THE APPLICATION CAN BE FOUND ON THE WEBSITE.
- IF YOU NEED ASSISTANCE WITH YOUR SSI APPLICATION, THE LOCAL AGING AND DISABILITY RESOURCE CENTER IS AVAILABLE TO ASSIST YOU.

THE LOCAL AGING AND DISABILITY RESOURCE CENTER IS:

1345 RIVER BEND DRIVE SUITE 200 DALLAS, TX 75247 PHONE: 888-743-1202

TOLL FREE: 1-855-937-2372
If you are located in another county go here: COUNTY SERVED: DALLAS

https://www.hhs.texas.gov/services/aging/long-term-care/aging-disability-resource-center/find-adrc to locate your specific resource center.

MEDICAL WAIVERS

CALL 1-877-438-5658 TO ADD YOUR CHILD OR CHECK ON/MAINTAIN STATUS ON THE WAIVER LIST. A WAIVER HELPS MEDICAID PROVIDE FUNDING FOR LONG-TERM HOME AND COMMUNITY SERVICES SUCH AS DAILY PERSONAL CARE, NURSING CARE, HOME/CAR MODIFICATIONS, RESPITE CARE AND CERTAIN THERAPIES. THE WAIVER ALSO MEANS THAT SOME OF MEDICAID REQUIREMENTS ARE NOT CONSIDERED FOR EX. FAMILY INCOME.

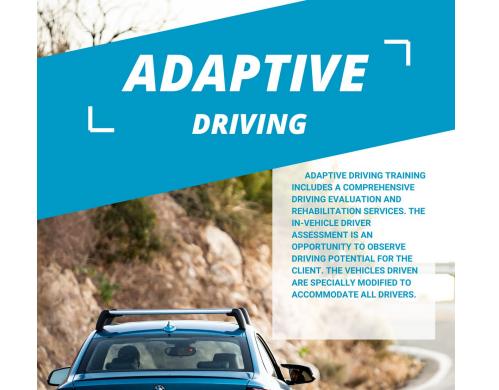
GO HERE TO FIND OUT MORE ABOUT MEDICAID WAIVER PROGRAMS
HTTPS://WWW.NAVIGATELIFETEXAS.ORG/EN/INSURANCE-FINANCIALHELP/TEXAS-MEDICAID-WAIVER-PROGRAMS-FOR-CHILDREN-WITH-DISABILITIES

If your child is currently on the STAR kids Medicaid program, then they can remain on that program until age 21. Your service coordinator will reach out to you when your child turns 20 in order to transition over to the STAR Plus+ Waiver.

A WAY TO SAVE

TEXAS ABLE SAVINGS PROGRAM

This savings plan is made for Texans with disabilities to help plan for financial independence through the Texas Achieving a Better Life Experience also called the Texas Able account. Eligible Texans of any age whose disability occurred before the age of 26 can participate in the Texas Able program Texas ABLE | Savings Program for Texans with Disabilities for eligibility requirements. You can save money in an ABLE Account and still be able to have all of your Medicaid or SSI benefits. It is important to read all the fine print and you may want to consult a lawyer for more understanding.



Adaptive Driving lessons and Evaluation

Frequently Asked questions



Does insurance cover it?

The ability to drive is not considered a medical necessity; therefore, Medicare and most commercial insurances do not cover the cost. Your options are Worker's Compensation, the Texas Workforce Commission and/or paying out of pocket.



I passed the driving evaluation. does that clear me to drive?

No. The Texas Department of Public Safety is the ONLY legal authority that can put on your permanent driving record that you are safe to return to driving.





Is a Driving eval necessary?

Before a person requiring adaptations takes their full driving test, they will need to take a Driving Assessment, which will determine exactly what adaptive controls they will need. This can be done through adaptive driving



Are there any options other than adaptive driving?

There are disability driving instructors, also sometimes called specialist driving instructors, they specialize in training driver's requiring adaptations. These instructors have expertise in adaptive driving techniques and a thorough knowledge of all of the different types of adapted controls and vehicle modifications. Many are freelance.



BAYLOR SCOTT AND WHITE ADAPTIVE DRIVING LOCATIONS

Dallas 909 N

909 N Washington Ave. Dallas, TX 75246 214-820-9225

> Frisco 2990 Legacy Drive Frisco, TX 75034 469-888-5172

Las Colinas 7701 Las Colinas

Ridge, Suite 110 Irving, TX 75063 214-574-7848

> Arlington 800 W. Randol Mill Road Arlington, TX 76012 817-960-6100

Fort Worth 1301 Pennsylvan Avenue Fort Worth, TX 76104 817-250-2760

> Willow Park 101 Crown Pointe Blvd. Willow Park, TX 76087



720 Bray Central Drive, S McKinney, TX 75069 Fax: (469) 343-1463

ADAPTIVE DRIVING

FACTS TO KNOW

- Under the ADA, Departments of Motor Vehicles cannot deny someone a driver's license solely because of a disability.
- You can receive your permit at age 15 and receive your license at age 16, disability status does not affect this.
- Drivers needing adaptations must pass a theory test, which typically includes a multiple-choice section and a perception skills section, and a practical road test with an instructor that specializes in adaptive driving training.
- ➤ Drivers needing adaptations take the same test as drivers that do not need modifications and are still required to take the classroom education course either through a commercial driving school, or through an approved parent-taught course if you are between the ages of 15 and 18.
- Under the ADA individuals who rely on hand controls to operate their cars and trucks have an equal right to test drive their vehicles before purchasing them.

SERVICE DOGS

Canine Companions

https://canine.org/location/south-central/





Canine companions is a national organization that serves adult and children, veterans and provides service dogs to health care facilities, criminal justice and educational settings."



The local South Central Training Center is here in the metroplex at:
The Baylor Scott and White Health - Kinkeade Campus in Irving, TX.
7710 Las Colinas Ridge
Irving, TX 75063
(214) 259-4700 Voice
(800) 577-BARK (2275) Toll-free



Once you are accepted, you will be invited to a two week training class where you will meet, play, and try out different training exercises to find the dog that is the best fit for you! The campus also provides lodging during the training class if needed.



A lifetime of support



EQUIPMENT

TO DO LIST.

WHEN YOU NEED NEW A WHEELCHAIR

OR

WHEN SOMETHING ON YOUR W/C BREAKS...

- First contact the wheelchair vendor that originally provided you the wheelchair they may be able to help with replacement parts or anything that might be covered by your insurance.
- If it has been a while since you got your wheelchair or that vendor is requesting that you to be evaluated by a seating specialist. Contact your primary physician for a
- The Wheelchair Seating Clinic at Baylor Scott and White Institute for Rehabilitation
 in downtown Dallas can help with a custom wheelchair evaluation. The therapists
 measure you for correct wheelchair fit, they also take a map of seating pressure to
 recommend a good quality cushion to protect your skin and match the type of
 wheelchair with each individual patient's needs based on their daily activity level.
- If you would like assistance from the Baylor Scott and White Institute for Rehabilitation Seating Clinic ask your physician to fax over a Physical Therapy referral stating for Seating Clinic/Eval and Treat
- Fax number 214-820-9522 and Phone number 214-820-9364
- The Clinic will contact you from there to set up an appointment and will arrange for a wheelchair vendor to be present at your visit.

NOTE.

Neuro Assistance Foundation 2320 Bridgewood Drive, Keller, TX 76262

(817) 741 0444

OTHER EQUIPMENT NEEDS

supply you need.

- First contact the DME company that originally provided you with your needed health supplies.
 If it has been a while since you talked to or received
- If it has been a while since you talked to or received equipment from that DME company contact your Service Coordinator from your health insurance plan and they can help with getting you in contact with new recommendations of DME companies that take your insurance and provide the specific type of health
- Also contact the North Texas Spina Bifida
 Association's office 972-238-8755 we might have what
 you need in our supply closet!

"Neuro Assistance Foundation serves the Spinal Cord community by providing minor modifications to the home or vehicle, financial assistance towards rehabilitative services, and providing much needed durable medical equipment. These are basic needs for individuals living with Spinal Cord injuries or disabilities and creates a safe environment that we hope deters future hospital stays!

WHEN YOU NEED NEW ORTHOTICS OR

WHEN YOUR ORTHOTICS

NEED REPAIR

The best source of finding a reputable orthotist in your specific living area is to go to the American Board for Certification in Orthotics, Prosthetics & Pedorthics https://abcop.org/abc-directory

If you would like to search by Certified individual see below the only information needed is City, State, Country or just enter your Zip Code

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If you would like to search by Accredited Facility, see below the only information needed is City, State, Country or just enter your Zip Code





Some Local Medical Providers



FINDING THE RIGHT DOCTOR THAT FITS YOU CAN BE HARD, AND PART OF THE SEARCH PROCESS IS ASKING OTHERS FOR REFERRALS. THE FOLLOWING ARE SOME PHYSICIANS THAT OTHER MEMBERS OF THE SPINA BIFIDA NORTH TEXAS COMMUNITY HAVE FOUND FOR THEIR CARE. THE SBANT CANNOT LEGALLY ENDORSE ANY SPECIFIC HEALTH CARE PROFESSIONAL HOWEVER THESE ARE SOME LOCAL PROVIDERS AVAILABLE IN THE AREA THAT HAVE BEEN SHARED, THERE ARE MANY OTHERS AND PLEASE CONTACT RLEE@SPINABIFIDANT.ORG WITH ANY ADDITIONAL PHYSICIANS THAT YOU WOULD LIKE TO CONTRIBUTE.

OBGYN

Baron Atkins, M.D. 811 Interstate 20 W #218 Arlington, Texas 76017

UROLOGIST

Dr. Matthew Wilner Urology Clinic of North Texas

UROLOGIST

Dr. Brian Feagins 10501 N Central Expy #200 Dallas, TX 75231

UROLOGIST

Dr. Gary Lemack UTSW

UROLOGIST Pediatric Spina Bifida and Neurogenic Bladder Center (up to age 26) locations in Plano, Dallas, & Rockwall 844-4CHILDRENS

Dr. Joseph Beshay Medical City Dallas

NEUROLOGY Dr. Write UT Southwestern

NEUROLOGY

Dr. Write UT Southwestern

NEUROLOGY Lone Star Neurology

multiple locations in Allen, Carrolton, Dallas, Denton, Ft. Worth, Frisco, Frisco at the Star, Garland, Grapevine, McKinney, Richardson https://lonestarneurology.net/

For an appointment, call 214-619-1910.

