

PATHWAYS TO ADULTHOOD

... providing participants with tools and information needed to help plan a good life for youth after graduation.



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*In Memory of
Rosemary Alexander*

Her life was a blessing,
her memory a treasure,
her kindness and guidance
missed beyond measure.

Welcome to Pathways To Adulthood

- Please mute your phones.
- The PowerPoint will be on the Texas Parent to Parent website: www.tx.p2p.org.
- Words highlighted and most images are hyperlinked to a resource.
- We would love to see your faces, please turn your cameras on! :0)
- Please type all questions in the chat box.
- We will try to answer all questions at the end of each session.
- If questions aren't answered, email Cynda Green at: Cynda.green@txp2p.org.

Sponsors



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GOAL FOR TODAY

Review tips 6-10 for creating a meaningful life for your youth.

Provide resources that point you in a direction to learn more.



- 6) **Consider Supports Needed For Success**
- 7) **Learn About Publicly Funded Programs**
- 8) **Keep An Open Mind & Let Go**
- 9) **Understand Eligibility Requirements & Your Rights**
- 10) **Create a Meaningful Day**



6. Explore Supports Needed For Success

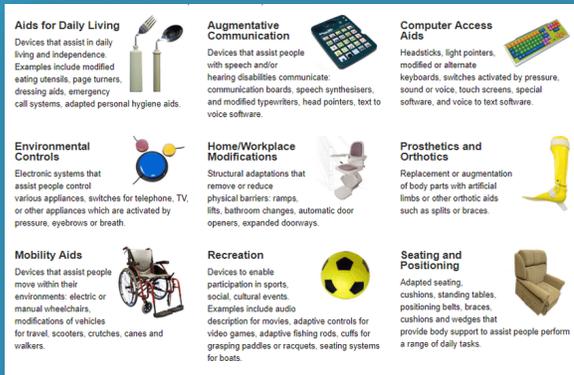
- assistive technology and adaptive aids
- decision making after turning 18
- estate planning
- **natural supports**
- pediatric to adult healthcare transition
- self-determination and **self-advocacy**
- transportation
- to **vote** or obtain a **Texas Identification Card**

“Don’t let your
needs determine
your dreams,
let your dreams
determine
your needs.”

– Colleen Tomko

Independence is not measured by the
number of tasks we can do without
assistance, but by the quality of life we
can live with assistance.

Americans with Disability Act, 1990



Can my child benefit from assistive technology or adaptive aids?

Assistive technology and adaptive aids provide creative solutions that enable an individual with disabilities to be more independent, productive, and included in society and community life.

It provides a way for a person to do something that they were once unable to.



access

dressing

communication

computer access

eating, drinking and cooking

environmental controls

household aids

hygiene

lifting, transferring, standing

medication

prompts

recreation

safety and security

seating and positioning

sensory processing and
cognition

time management

transport

vocational aids and equipment

walking and mobility aids





Resources And What We've Learned About AT and Adaptive Aids

Tips

assistive technology is the term used in special education

adaptive aids is the term used in adult life

search using the term “adaptive” before the item you’re looking for

solutions are limited by our imagination

Resources

[Center on Technology and Disability](#)

LEAP: [Living With Technology](#)

Navigate Life Texas – [AT and Adaptive Equipment](#)

[Texas Technology Access Program](#)



Will my child need support to make decisions after turning 18?

84th Texas legislature mandated that probate courts consider alternatives to guardianships and supports and services before a guardianship is created.

Supported Decision Making

- **SDM** was placed into statute as an alternative to guardianship
- allows individuals with disabilities to make their own decisions and stay in charge of their lives, while receiving the help they need to do so

Scope of SMD Agreement
Authority of the supporter

Alternatives To Guardianship

Medical Power of Attorney

Durable Power of Attorney

Declaration for Mental Health Treatment

Representative Payee

Joint Bank Account

Management Trust

Special Needs Trust

Designation of a guardian before the need arises

Alternate forms of decision-making based on person-centered planning

Supports and Services – TEC Sec. 1002.031

Texas Estates Code Sec. 1002.0015 - Alternatives to Guardianship

Guardianship

A relationship established by a court of law between a person (ward) who needs help (incapacitated) and a person or entity named to help the person in need (guardian).

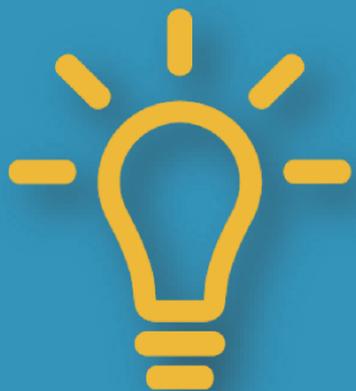
- guardian of the estate, full or limited
- guardian of the person, full or limited
- guardian of the person and estate
- temporary guardian

A Texas Guide to Adult Guardianship, Texas HHS

“Because having a guardian takes away a person’s rights, it should be the last and the best available choice.”

- A Texas Guide to Adult Guardianship, Texas HHS

- guardians advocate for, protect and support the ward
- attorney and other legal fees involved
- creates a three-party relationship
- reports or accountings to the court are required annually
- letters of guardianship expire if not renewed annually
- terminating or modifying the terms of the guardianship requires the services of an attorney and the court



What we've learned about guardianship and alternatives to guardianship

it is best to research all options before deciding the best option for your family

a guardianship does not equal safety

everyone has the right to succeed and fail

take advantage of every opportunity for your child to practice decision-making

evaluate your child's ability to make decisions as they enter adulthood

assess your ability to "wait and see"

knowing who to ask and asking for help is a strength

no one does everything by themselves; we all have interdependent relationships and use supports

how you support your child can impact waiver program services



ESTATE PLANNING

What will my
child need
when I am
gone?

Estate planning for a child with a disability
or special health care needs comes
with unique challenges.

Fortunately, with good estate planning
and the use of tools designed to help your child
maintain benefits, you have the chance to
provide for your child's future.

Letter of Intent 88 item checklist

A letter of intent gives parents a venue to communicate vital information to future caregivers in their absence.

- does not require an attorney to create
- revise annually, or more often if needed
- includes detailed information about your wishes and knowledge about your child
- is not a legally binding document

Special Needs Trusts

- financial management tool that allows a person with a disability to accumulate funds over \$2000 and remain eligible for benefits
- protect assets so not in your child's name
- many types, seek help

The Arc of Texas Master Pooled Trust

- a pooled special needs trust
- funded and non-funded accounts

ABLE Account

- 529 tax-advantage saving account
- person with a disability must be diagnosed before age 26
- annual limits for contributions
- money used only on qualifying disability-related expenses
- can open an account in another state

Estate Planning Resources

ABLE Accounts

- ABLE National Resource Center – ANRC
- Texas ABLE

Financial Planners

- Certified Financial Planner – CFP
- Chartered Special Needs Consultant – ChSNC



How can we
prepare for the
transition from
pediatric to adult
healthcare?

Change is Coming...

Communication

transfer of rights at 18

encourages youth self-direction

Doctors

ask your doctor for a referral

talk with your friends

Health Insurance

changes after age 18

extending insurance coverage after age 26 is
not automatic



Healthcare Transition Resources

Baylor College of Medicine Annual Conference

Healthcare Guides

- Transition to Adulthood: A Health Care **Guide** for Youth & Families
- A Family **Toolkit**: Pediatric-to-Adult Health Care Transition
- Transition **Checklist** for Teens

Texas HIPPA Form

Texas Health Insurance Premium Payment Program

Texas Parent to Parent Care Notebook

Web-Based Resource

Got Transition?

Smooth Moves – Youth Health Transition

THERE IS ONLY ONE
SUCCESS -- TO BE ABLE
TO SPEND YOUR LIFE
IN YOUR OWN WAY.

- CHRISTOPHER MORLEY

How can I foster
my child's
self-determination and
self-advocacy

Self-Determination describes a person's right to make choices about their own life, to have the same rights and responsibilities as everyone else, and to speak and advocate for themselves. It is about being in charge, but it's not necessarily the same thing as self-sufficiency or independence.

Based on 5 principles

Freedom – to decide how you want to live and plan your future

Authority – to decide how to spend money given to you

Support – to organize resources in ways that are life enhancing and meaningful to you

Responsibility – wise use of public dollars and awareness of contributions individuals with disabilities can make

Confirmation – the role self-advocates must play in systems redesign

Growth Mindset

start early

have high expectations

don't let your child's disability get in the way of taking responsibility

encourage your child to explore their interests

encourage problem solving

teach your child about their disability

embrace reasonable risk taking

Why?

People with disabilities with higher levels of self-determination are healthier, more likely to be employed, earn more per hour, and experience more independence.

Wehmeyer & Schwartz

When denied self-determination, individuals with disabilities are more likely to feel helpless, hopeless, and passive, and are at greater risk of abuse.

Khemka, I., L.Hickson & G. Reynolds 2



Self-Determination And Self-Advocacy Resources and What We've Learned

Tips

self-determination is a natural part of life

it will look different for each person

should be fostered throughout life

self-advocacy is the counterpart of **self-determination**

Resources

Fostering Self-Determination Among Children and Youth with Disabilities—Ideas from PARENTS for PARENTS

Green Mountain Self-Advocates **Resource Library**

I'm Determined

The Center for Self-Determination

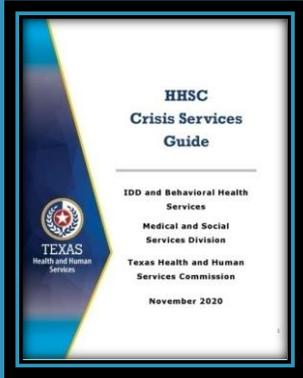
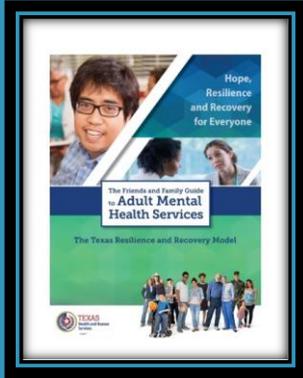
Making it easier.

Are you familiar with
all the programs
available?

7. Learn About Publicly Funded Programs and Services

“The wait for publicly funded services can be long. Put your child on the wait lists before you need the service.

Otherwise, you may find yourself without services needed for success.” - *unknown*



Adult Mental Health Services

National Suicide
Prevention Hotline
800-273-8255

Service Options

- case management
- co-occurring psychiatric
- substance use disorder
- counseling (CBT & ABT)
- crisis services
- employment and education
- forensic services
- housing
- medication management
- rehabilitative and skills training
- specialized programs

Local Behavioral Health Authority – 2 in Texas

Local Mental Health Authority – 37 in Texas

AMHS Eligibility Requirements

- Texas resident
- meet financial criteria
- meet uniform assessment qualifications

Community First Choice – CFC Services

CFC Services

an entitlement program
that provides basic
attendant and habilitation
services for persons with
disabilities and are
available to Medicaid
recipients with an
institutional level of care.

launched in 2015

eligible Medicaid
recipients with disabilities

provided through LTSS
waiver programs

service options include

Emergency Response
Services - ERS

Personal Assistance
Services – PAS

Habilitation – HAB

Support Management

General Revenue – GR IDD Services

provided by or through a Local IDD Authority ([LIDDA](#))

services intended to help a person remain in their own or family home

IDD eligibility required (must meet one of the criteria)

- IQ, adaptive behavior, evidence of disability before 18
- Autism Spectrum Disorder – ASD
- NF resident eligible for specialized services for ID or related condition
- be eligible for early childhood intervention services

[array of services](#)

not all GR services are available in all areas of the state

Long-Term Services and Supports

Long-Term Services and
Supports - **Texas
Medicaid State Plan**

Texas Long-Term
Services and Supports
(LTSS) **Medicaid Waiver
Programs**

Texas **Title XX**
Community
Services and
Supports

All LTSS programs have
different eligibility
requirements, service
options, funding
amounts, and rules
that define who can
provide a service.

[Compare Texas LTSS Programs](#)

Medicaid Wavier Programs

7 Waiver Programs

CLASS

DBMD

HCS

MDCP

STAR+PLUS

TxHmL

YES

Put your child on the list/s

CLASS, DBMD, MDCP -
transitioning to STAR Kids
call 877-438-5658

HCS & TxHmL
call your **Local IDD Authority**

YES Waiver
call your Local Mental Health
Authority – **LMHA**

Waiver Funding Paths

1) Interest List / “Wait List”

first come, first served

2) Promoting Independence

HCS Diversion Slot

transition from an institution to the community

Texas [Promoting Independence Protocol](#) for offering an HCS Diversion Slot

HCS Diversion Slot

has an intellectual or developmental disability (IDD) and is at imminent risk of admission to an institution

is leaving a state hospital and who is at risk of re-institutionalization

meets qualifications for the [HCS Reserved Capacity Group](#)

number of slots determined during each legislative session

Interest list numbers, Summary Counts, & Percentages – May 2022

Program	Individuals On An LTSS Waiver Interest List	Individuals Receiving LTSS Waiver Services	% Receiving LTSS Services
CLASS	78,775	11,723	14.9%
DBMD	1,292	150	11.6%
HCS	109,641	18,947	17.3%
MDCP	7,174	242	3.4%
STAR+	17,105	6,920	★ 40.5%
TxHmL	97,718	14,299	14.6%

LTSS Medicaid Waiver Slots Allocated For Each Biennium

LTSS Medicaid Waiver Program	2022 – 2023 Legislative Allocation	2020 - 2021 Legislative Allocation	2018 - 2019 Legislative Allocation
CLASS	381	240	-0-
DBMD	6	8	-0-
HCS	542	1320	-0-
TxHmL	471	-0-	-0-
MDCP	42	60	-0-
STAR+	42	-0-	-0-

[Interest List Reduction Summary](#)

Why the STAR+PLUS HCBS Waiver is an outlier

- Managed Care Environment vs. Fee-for-Service by HHSC
- MCOs agreed to place **SSI-eligible** and **service-qualified** people in the waiver without a wait
- People who are on the STAR+PLUS HCBS interest list do not receive SSI



Medicaid
Waiver
Programs:
What We've
Learned

eligibility is not determined until services are offered

some programs do not consider parental income

interest list - annual contact required

your child can be on more than one interest list

contact your LIDDA to request a diversion slot

number of slots funded determined by the Texas legislature during each legislative session



Medicaid and Medicare

Medicaid is acquired
through...

income eligibility

HCBS waiver programs

SSI

Medicaid Buy-In

adults

children

Medicare is acquired
through...

age eligibility

Part A – hospital

Part B – medical

Part C – prescription
drug

SSDI

child disability benefits

**end stage renal
disease**



Supplemental
Security
Income – SSI and
Social Security
Disability
Insurance – SSDI

Social Security
Administration Disability

Benefits: SSI and SSDI

While these two programs
are different in many
ways, both are
administered by the Social
Security Administration
and only individuals who
have a disability and meet
medical criteria may
qualify for benefits under
either program.

SSI Eligibility

- 1) documented proof of a
qualifying disability
- 2) income
 - parental income
before 18
 - persons income 18+
 - ready assets - under
\$2,000

Benefits

Texas SSI benefit

- \$841 maximum benefit
- \$560 or less, many variables considered
- cover food, shelter and clothing

How to Apply

in person

online

phone: 800-772-1213

Aging and Disability Resource Center

can help you apply

SSI Benefit Determination Considers

if you pay your “fair share” – household expenses divided by the number of people in the home

loans of In-kind Support and Maintenance - ISM Loans

your living arrangement

Student Earned Income Exclusion

Income Exceeds Limit? Contact

Disability Rights Texas PABBS Program

Texas Parent to Parent – 866-896-6001

SSDI

Pays benefits to you and certain family members if you are “insured” – meaning that you worked long enough and you paid Social Security taxes.

May move from SSI – SSDI when enough work credits are acquired

of work credits vary by age

Medicare after 2 years

Disabled Adult Child - DAC

If disabled before age 22, DAC may qualify for benefits based on a parent’s work history when parent starts to draw Social Security.

- 50% of parent’s monthly SS
- Medicare after 2 years
- DAC must receive SSI when moving to SSDI

To maintain eligibility for Medicaid if SSDI income exceeds limit, claim Medicaid under section 1634(c) of SS Act; reapply for Medicaid and write “DAC” at top of application.



SSI And SSDI What We've Learned

follow income guidelines

Compassionate Allowances conditions help reduce the wait time to reach a disability determination

report all income and required changes on time

keep ALL paystubs and SSA communications

learn about **Ticket to Work** and **WIPA – The Red Book – A Guide to Work Incentives** is a good resource

ABLE accounts and Special Needs Trusts can protect assets over \$2,000

Other Publicly Funded Programs

Affordable Connectivity Program

Blind and Visually Impaired Services

Children with Special Health Care Needs Program

County Indigent Health Care Program

Epilepsy Programs

Hemophilia Assistance Program

Primary Health Care Services Program

SNAP Food Benefits

Specialized Telecommunication Assistance Program

Texas Department of Housing and Community Affairs – TDHCA
Programs

Texas Health Insurance Premium Payment Program

Texas Workforce Commission

8. Keep An Open Mind And Let Go

a comfort zone
is a beautiful place,
but **nothing**
ever grows there.



confidence
dreams
excitement
**exploration of
new things**
opportunity
purpose
self-discovery

Dignity of Risk...

the legal right of every person, including people with disabilities, to make choices and take risks in order to learn, grow and have better quality of life.

Inherent to the idea of dignity of risk, is the idea that life experiences come with an element of risk, which even the best planning and support can not eliminate.



Letting go,
what we've
learned

presume competence

avoid ableism

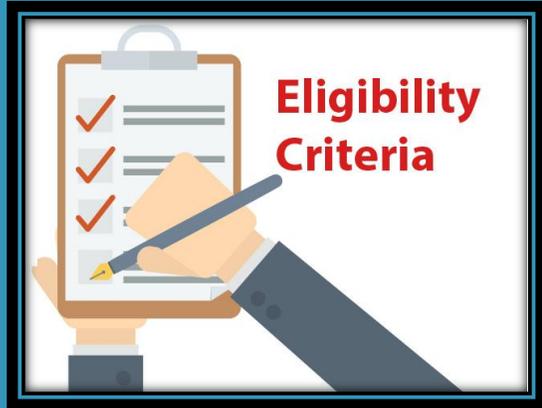
start slow – take baby steps

take advantage of co-curricular and extra-curricular activities – if supplemental aids and services are needed, write them into the IEP

take calculated risks, there is dignity in risk

you don't have to do what others suggest or have done before you

consider failure as an opportunity to learn, life lessons are valuable



9. Understand Eligibility Requirements & Your Rights

Community Activities and Services

Post-Secondary Education Programs

Protections under Disability Rights Laws

Public School Services – IDEA, SBOE, Commissioner’s Rules, Texas State Law

Publicly Funded Programs

Scholarships

Section 504 of the ADA

State Agency Programs



Statewide Organizations & Informational Websites

Association for University Centers on Disability ([AUCD](#))

Coalition of Texans with Disabilities ([CTD](#))

Disability Rights Texas ([DRTx](#)) – State Protective and Advocacy (PA) Agency

Partners Resource Network – State Parent Training and Information ([PTI](#))
Network

Texas Council on Developmental Disabilities ([TCDD](#))

Texas Governors Committee on People with Disabilities ([GCPD](#))

Texas Parent to Parent ([TxP2P](#))

[Navigate Life Texas](#) – across the lifespan

[Parent Companion](#) – birth to 5

[Texas Project First](#) – special education

[The Legal Framework](#) – special education

[Understood](#) – special education



10. Create a meaningful day.

important “to” and
important “for” is present
active circle of support
included in community
meaningful relationships
risk is acknowledged as a
natural part of life

ESC-Region 13 student
survey 1 year after
graduation found...

1/3 in educational setting
1/3 in work setting
1/3 at home, doing nothing

**USE YOUR SCHOOL YEARS
TO LOOK AHEAD AND PLAN**



We Are Here To Help YOU!

“With the support of
another parent we begin
to feel we will survive
because we know
another parent who has.”

Pathways To Adulthood Transition Program: assists families to plan a good life for their youth with disabilities after graduation from public school, and provides support, information and tools for carrying out this plan.

Texas Network Connections: Personal Networks of Support create a circle of support around a person at risk for isolation.

TxP2P Transition Center of Central Texas: assists families (**statewide**) to develop high quality lives for their youth and adults with disabilities after they graduate from public school.

TxP2P Transition Inventory: this inventory will help you determine what steps to take as you work for quality of life for your child with a disability.