Pathways to Adulthood
Part - 1

The future is not something we enter.
The future is something we create.

Texas Parent to Parent
Pathways To Adulthood Team
Welcome to Pathways To Adulthood

Please mute your phones.


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, please email Cynda Green at: [Cynda.green@txp2p.org](mailto:Cynda.green@txp2p.org).
Goals for Today

Pathways To Adulthood (PTA) is designed to give participants the tools needed to plan a good life for your youth after graduation.

- Estate Planning
- Facts and Possibilities
- Healthcare Transition
- Managing Emotions
- Self-Determination
- Transfer Of Rights
In Memory of Rosemary Alexander

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

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Thank You To Our Partners…

This project is supported by the Texas Council for Developmental Disabilities (TCDD) through grant number 2101TXSCD00 from the U.S. Administration for Community Living (ACL), Department of Health & Human Services, Washington, D.C. 20201. Grantees receiving government sponsorship are encouraged to express their findings and conclusions. Opinions do not necessarily represent official TCDD or ACL policy.
TExas parent to parent presents

Pathways to Adulthood

We invite you to join our Two Part Pathways to Adulthood series via Zoom!

Transition to adulthood can be overwhelming, there are many new things to consider, decisions to be made and, we can help you find the tools necessary to start your youth transition planning. Our two series workshop will offer an overview of the following topics:

Part One
- Managing Emotions
- Facts and Possibilities
- Health Transition
- Self-Determination
- Transfer Of Rights
- Estate Planning

Part Two
- Publicly Funded Programs and Services
- Person-Centered Planning
- Public School Transition Services
- Personal Networks of Support

Saturday September 11, 2021 from 1:00 - 2:30pm
Click here to register

Saturday September 25, 2021 from 1:00 - 2:30pm
Click here to register

This project is supported by the Texas Cocon of Developmental Disabilities (TDD) through grant number 2T17DDK258809 from the U.S. Administration for Community Living (Acl), Department of Health & Human Services, Washington, DC, 2021. Opinions or views, including those of sponsors, are encouraged to express their findings and conclusions. Opinions do not necessarily represent official TDD or ACL policy.
Fear will try to keep you from taking that first step. Don’t give in to fear, DO IT afraid.

~ Joyce Meyer
What is standing in your way?

- denial
- discouragement – lack of confidence
- fear of the unknown
- feeling overwhelmed or burned-out
- lack of resources and/or options
- limited exposure of possibilities
- time to think about transition later
- willingness to let go
What does it take to move forward?

- change in family dynamics
- new opportunities
- school request
- youth request
- crisis – that’s why you’re here, to plan thoughtfully not in crisis mode.

“The best way to get started is to take the first step with dream empowered optimism.”

~Debasish Mridha
Where do I start?

• connect with other families and self-advocates
• read a Good Life, by Al Etmanske
• visit the Navigate Life Texas website section - Transition to Adulthood
• contact Texas Parent to Parent – TxP2P at 866-896-6001 or visit Pathways To Adulthood
• talk with school staff; including the Transition and Employment services Designee – TED
What Do We Know About The Future?

- it is coming and will be here before you know it
- it is for you and your child to create
- it happens as result of what you do TODAY!
- without a **vision**, without a destination, without a goal, you are unable to pick a direction or plot a course of action to get “there”
“Your belief determines your action, and your action determines your results, but first you have to believe.”

~ Mark Victor Hansen
What Do You Believe?

Strongly Disagree

1. I believe my child can communicate
2. I believe my child can learn
3. I believe my child can contribute to society
4. I believe my child can live a self-determined life
5. I believe my child can live independently
6. I believe my child can work
7. I believe my child can actively participate in the community

Strongly Agree
Where will my child learn?
prepare for further education, employment and independent living

K-Graduation Options
- Home School
- Private School
- Public School Pre-K-2 [pg. b-26]
- Public School 18+ program

Post Secondary Education – PSE
- Adult Education Classes
- Certificate Programs
- College/University
- Specialized Classes-Courses
- Vocational - Trade Schools

Special Education Resources
Organizations
- Partners Resource Network
- SpedTex

Other Parents
Publications
- Notice of Procedural Safeguards
- Parents Guide to the ARD Process
- Special Education Rules and Regulations

Web-Based Resources
- Navigate Life Texas – Education and Schools
- Texans for Special Education Reform (TxSER)
- Texas Project First
- Texas Transition Student-Centered Transitions Network
- The Legal Framework
- Wrightslaw
We must educate kids in learning environments which look like the ones we hope they will live in as adults, because as adults they are likely to live in environments that look like the ones they were educated.

- Charlene Comstock-Galagan,
Post Secondary Education changes, tips and resources

**Changes**
- students must enter college on their own merit – No IDEA
- 504 accommodations available – must be requested
- students are expected to advocate for themselves and are protected under FERPA
- the Parental Affidavit Form can be used by qualifying families to view elements of their child's academic records

**Tips**
- know and plan by 9th grade the credits and testing required for college eligibility
- the Continuing Education Office is often the most helpful resource on a college campus
- become familiar with the campus disability services office and how they can help you
- learn about the various PSE options and new initiatives

**Resources**
- **Web-based**
  - HEATH Resource Center
  - Think College
- **Financial Aid**
  - FASFA
  - TWC – VR Program
- **Scholarships**
  - Affordable Colleges Online
  - OnlineSchools.org

**Rethinking College** is a short film that explores the movement to include students with am ID in higher education.
Where will my child live – call home?

Parent arranged options
- Co-Housing
- Cooperative Housing
- Family Consortium
- Family Home

Individualized Housing

State funded residential options
- Community ICF-IID
- HCS Group Home
- Host Home/Companion Care
- Large State Run ICF-IID – State Supported Living Center (SSLC)

Privately Funded Communities

Living My Own Life – is a film on independent living and stories of triumph.
Resources to Help Create a Home

Organizations – Programs

- **AIM** – Adults Independent and Motivated
- **Community Homechoice Program**
- Community for Permanent Supported Housing (CPSH)
- Section 811 Supportive Housing for Persons with Disabilities **Program**
- Texas Department of Housing and Community Affairs (TDHCA) **Programs**

Web-based:

- **Navigate Life Texas: Housing Choices for Young Adults with Disabilities**
- **Texas Parent to Parent: How-to for Setting Up A Supported Residence**
- **Texas Reality Check**

Publication:

Where will my child work?
initiative, strategies and supports

**Employment First**

“Believes that all citizens, including individuals with significant disabilities, are capable of full participation in integrated employment and community life.”

Department of Labor Office of Disability Employment Policy – DOL ODEP, Employment First

**Strategies**

- [Customized Employment](#)
- [Integrated Employment](#)
- [Self-Employment and Entrepreneurship](#)
- Sheltered Employment – 14 (c) subminimum wage certificate

**Supports**

- accessible technology
- accommodations
- communications access
- flexible work arrangements
- natural supports
- personal assistant services
- transportation
- Universal Design

*Bottom Dollars* – is an award-winning documentary film on sub-minimum wage and employment.
Our Assumptions About Work

- everyone deserves the right to work... given the right environment and supports
- job creation can take time, creativity and planning
- look past typical work stereotypes
- your child is ready to NOW!

Employment Resources

Local IDD Authority – LIDDA

Texas Employment First

Texas Long Term Services and Supports (LTSS) Waiver Programs
- Employment Assistance – finding a job in the community
- **Supported Employment** – ongoing job supports to sustain integrated employment

**Texas Reality Check** – cost of living expenses and amount of money needed to pay them

Texas Workforce Commission – TWC
- TWC Pre-Employment Transition Services – activities designed to support students (14-22) with disabilities in the career development process to increase the success in obtaining employment after graduation from high school. – **Pre-ETS Guide**
- TWC Vocational Rehabilitation Services – services for persons with disabilities to help them prepare for, obtain, retain or advance in employment. – **VR Services Manual**

U.S. Department of Labor Office Disability Employment Policy – DOLODEP
What about leisure activities and relationships?

**Leisure**
- clubs
- community or city sponsored activities
- Day Habilitation program
- exercise programs
- faith based activities
- recreation center
- Self-Advocacy Group
- specialized programs
- sports programs
- volunteer

_Are You Accessing Your Natural Supports_ By Dee Blose

**Relationships**
- acquaintances
- co-workers
- dating/romantic
- direct support professionals
- faith community
- family – immediate and distant
- friends
- medical providers
- club - team members

Building Social Capital 8-part [_YouTube Series_](https://www.youtube.com) By Al Condeluci
Can My Child Benefit from Assistive Technology or Adaptive Aids?

Assistive technology (AT) 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.

- accessibility
- communicate
- cook
- dressing
- environmental controls
- independent living
- learn – demonstrate knowledge
- medication
- mobility
- prompts
- recreation and leisure
- safety and security
- time management
- work

Resources

- LEAP: Living With Technology
- Navigate Life Texas – AT and Adaptive Equipment
- Texas Technology Access Program - TTAP
It has been suggested that preparation for the pediatric to adult healthcare transition should start by the time the patient is 12-14 years old.

**Change is Coming…**

**Communication**
- **transfer of rights** at 18
- encourages youth self-direction

**Doctors**
- ask your doctor for a referral
- talk with other parents

**Health Insurance**
- changes after age 18
- **extending insurance coverage** after age 26 is not automatic

What do I need to know about the healthcare transition?
Healthcare Transition Resources

**Care Notebook**
- Cooks Children’s Health Care Notebook
- Texas Parent to Parent Care Notebook

**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

**Baylor College of Medicine Annual Conference**
Chronic Illness and Disability: Transition From Pediatric to Adult-Based Care

**Texas HIPPA Form**
Authorization to Disclose Protected Health Information form

**Texas HIPP Program**
Texas Health Insurance Premium Payment (HIPP) program

**Prescription Assistance Programs**
- Good RX
- Navigate Life Texas – prescription assistance programs

**Web-Based Resource**
- Got Transition?
- Smooth Moves – Youth Health Transition
Will my child need support to make decisions after turning 18?

Alternatives to Guardianship

— **Advance Directives**: DMHT, Education POA, Living Will, MPOA, SDPOA
— **TEC Sec. 1002.031, Formal and Information Services and Supports**
— Joint Bank Account
— Alternate forms of decision-making based on **Person-Centered Planning**
— Special Needs Trusts
— **SS Representative Payee**
Supported Decision Making allows individuals with disabilities to make their own decisions and stay in charge or their lives, while receiving the help they need to do so.

**Benefits**
- person-centered
- protects civil rights
- improves quality of life
- affordable – courts are not involved

**A supporter CAN help the person...**
- gather information and understand the options, responsibilities, and consequences of their decisions
- communicate their decisions to the appropriate person/people

**A supporter CANNOT make a decision for the person. The supporter should...**
- act in good faith
- act loyally without self-interest
- avoid conflicts of interest

**Resources**
- Disability Rights Texas – [SDM](#)
- National Resource Center for Supported Decision Making – [NRC SDM](#)

**Supported Decision Making: Protecting Rights Ensuring Choices**, Jonathan Martinis reviews the importance of Supported Decision Making.
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).

Types

- guardian of the estate
- guardian of the person
- guardian of the estate and person
- temporary guardian

A Texas Guide to Adult Guardianship

- 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

“Because having a guardian takes away a person’s rights, it should be the last and the best available choice.” – Texas HHS
What we’ve learned…

- it is best to research all options for decision making – there are many things to consider
- everyone has the right to succeed and fail – there is Dignity in Risk
- take advantage of every opportunity for your child to practice decision-making – start early
- 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 in our lives
Self-Determination Define

**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.

**Principles**
- **Freedom** – to decide how one wants to live their life
- **Authority** – over a target budget and resources
- **Responsibility** – for the wise use of public dollars
- **Support** – to organize resources in a way that are life enhancing and meaningful to the individual
- **Confirmation** – of the important role PWD must play in a newly redesigned system

**Independence…**

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

Americans with Disabilities Act of 1990

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**Fostering Self-Determination Among Children and Youth with Disabilities—Ideas from PARENTS for PARENTS**
What supports will my child need and how will they be funded?

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

- Local IDD Authority – [LIDDA, IDD Services]
- Local Mental Health Authority – LMHA, [Adult Mental Health Services]
- Medicaid – [Medicare]
- Post-Secondary - [FASFA]
- [SNAP] Food Benefits
- Specialized Telecommunication Assistance Program - [STAP]
- [SSI – SSDI]
- Texas Department of Housing and Community Affairs – [TDHCA Low Income Programs]
- Texas Health and Human Services (HHS) Long-Term Services and Supports Programs
- Texas Health Insurance Premium Payment ([HIPP] Program
- Texas Workforce Commission – [TWC, VR] Program
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.
Estate Planning
special needs trusts, master pooled trusts and ABLE accounts

**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

**Master Pooled Trust**
- a **pooled special needs trust** managed by **The Arc of Texas**
- funded and non-funded accounts

**ABLE Accounts**
- 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

Certified Financial Planner – **CFP**
Chartered Special Needs Consultant – **ChSNC**
The goal of the TxP2P Transition Center of Central Texas is to assist families to develop high quality lives for their youth and adults with disabilities after they graduate from public school.

Parent to Parent Transition Center of Central Texas

assistance includes...

• a 1 to 2-hour consultation with parents of teens and adults with disabilities, either in person or via Zoom
• working through a transition inventory and helping the family to establish next steps and longer-range goals
• a resource bank to access during the 1-1 session and afterward
• transition peer mentors and information on important transition topics
• opportunities for a family to work on their youth’s future: join a Transition Action Group, start a personal network, become a transition mentor, or become a network facilitator.
Texas Parent to Parent presents

Introduction to Personal Networks

Texas Network Connections
Creating Community for People with Disabilities

Personal networks build a circle of caring volunteers around a person at risk of isolation. They promote planning and social opportunities in the present, assist with decision-making, and work to be sustainable after parents can no longer be available. Learn more about networks, how they benefit families and how the TxP2P Texas Network Connections Program can help you start a network.

Thursday
September 16, 2021
from 1:30 – 3:00 pm

Click To register
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Part Two

- Publicly Funded Programs and Services
- Person-Centered Planning
- Public School Transition Services
- Personal Networks of Support

Saturday
September 25, 2021
from 1:00 - 2:30 pm

To register click here
We are here to help!

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

Texas Parent to Parent
Pathways to Adulthood Team

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Learn more about the TxP2P Transition Resources

Pathways to Adulthood Transition
Texas Network Connections
Transition Inventory