THE FUTURE IS HERE:
WHY TRANSITION BEGINS NOW!

Cindi Paschall
Mom, Disability Justice Activist, Public Speaker
Goals for Today

Review the importance of planning early for adulthood.

Explore options.

Provide tools for planning and point you in a direction to learn more.
What we know...

The Future...

• starts now
• it is for you and your child to create
• happens as a result of what you do today
Disability...

disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to

a) live independently;
b) enjoy self-determination;
c) make choices;
d) contribute to society;
e) pursue meaningful careers; and

enjoy full inclusion and integration in the economic, political, social, cultural, and educational mainstream of United States society

– The DD Assistance and Bill of Rights Act
What Do You Believe?

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
“Your belief determines your action and your action determines your results, but first you have to believe.”

~ Mark Victor Hansen

Be a BIG believer!
Begin with the end in mind

It’s better to look ahead and prepare, than to look back and regret.

- Jackie Joyner-Kersee
Create a Vision

What do you want for your child now and in the future?

What does your child want?

dream

nightmare
Why Create a Vision?

direction  person centered
control     why
What’s in Your Tool Box

- Knowledge of Options
- Person-Centered Planning
- Person-Centered Thinking
- Self-Determination
- Transition Services
A lack of knowledge creates fear. Seeking knowledge creates courage.

- conferences
- family members
- people with disabilities
- publications
- research
- workshops

Knowledge of Options

A Good Life – for you and your loved one with a disability
By Al Etmanski
Where will my child...

Live: Call Home

State funded residential options
• Community ICF-IID
• HCS Group Home
• Host Home/Companion Care
• Large State Run ICF-IID

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

Individualized Housing

Privately Funded Communities

Living My Own Life – a film on independent living and stories of triumph.

Work

Work spares us from three evils... boredom, vice and need.

- Voltaire

• Customized Employment (CE)
• Entrepreneurship
• Integrated Employment
• Self-Employment
• Sheltered Employment 14(c) subminimum wage certificate

Bottom Dollars – a documentary film on sub-minimum wage and employment.
Employment First Initiative

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
Where will my child...

Learn

K-12
- Home School
- Private School
- Public School [pg. b-26]

Post-Secondary Education
- Adult Education Program
- College – University
- Historical Societies – Clubs
- Interest-Based Learning
- Life-Skills Program
- Vocational - Trade School

Spend Leisure Time
- Clubs
- Community or City Sponsored Activities and Events
  - Day Habilitation
- Faith Based Activities
- Recreation Center
- Self-Advocacy Group
- Specialized Programs
- Sports Programs
- Volunteer
Resources

**Special Education**

FAPE designed to meet the students unique needs and to prepare students for further education, employment and independent living

• Notice of Procedural Safeguards
• Partners Resource Network
• Texas Project First
• The Legal Framework
• Wrightslaw

**Post-Secondary Education**

• AHEAD
• Access College: The Student Lounge
• Going to College
• HEATH Resource Center at the National Youth Transition Center
• Think College

*Rethinking College* explores the movement to include students with ID in higher education.
Who will my child have a relationship with?

- Acquaintances
- Co-workers
- Dating/Romantic
- DSP
- Faith Community
- Family
- Friends
- Medical Providers
- Team Members

Loneliness is the only disability.

Building Social Capital 8-part YouTube Series
Will My Child Need a Guardianship?

WHAT
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

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

A Texas Guide to Adult Guardianship
Guardianship Reform

For the first time, the Texas legislature mandated that probate courts consider alternatives to guardianships and supports and services before a guardianship is created.

In 2015 the Texas Legislature passed four bills protecting the rights of persons with disabilities in the guardianship system.

- Alternatives to Guardianship – HB 39
- Court Initiated Guardianships – HB 1438 (section 10)
- Supported Decision-Making – SB 1881
- Bill of Rights of Wards – SB 1882

Navigate Life Texas: Legal Options for Age 18 and Beyond
Will Alternatives to Guardianship work?

- 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

Alternatives To Guardianship Texas Estates Code
Supported Decision Making

**SDM** 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.

**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

In the video - [Supported Decision Making: Protecting Rights Ensuring Choices](https://example.com), Jonathan Martinis walks you through the importance of Supported Decision Making
What supports will my child need and how will they be funded?

- Government funded LTSS programs
  - Long-Term Services and Supports Medicaid State Plan Programs
  - Long-Term Services and Supports Waiver Programs
  - Texas Title XX Services and Supports Programs
- Texas Health Insurance Premium Payment (HIPP) Program
- Local IDD Authority – LIDDA, IDD Services
- Local Mental Health Authority – LMHA, Adult Mental Health Services
- Medicaid
- Medicare
- Natural Supports
- Post-Secondary - Financial Aid & Scholarships, FASFA
- Specialized Telecommunication Assistance Program - STAP
- SNAP Food Benefits
- SSI – SSDI
- TDHCA low income programs
- Texas Workforce Commission – TWC, VR Program

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

Colleen Tomko
Change the Conversation!

Don’t ask: Can my child participate?

Do ask: What supports make my child’s participation possible?
Can My Child Benefit from Assistive Technology or Adaptive Aids?

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

For people without disabilities technology makes life easy. For people with disabilities technology make life accessible.

Center for Technology and Disability - CTD
LEAP: Living With Technology
Texas Technology Access Program - TTAP
Person-Centered Planning is a discovery process used to create an action plan that honors a person’s own vision for their life now and in the future (with input from their circle of support) and accounts for those things that are important to and important for them.
“When **Person Centered Thinking** is fully embraced, we abandon the idea that a person has to function at an arbitrary standard of ‘normal’ in order to make choices about their own life. We begin to look beyond predictable ways of choice-making and being in control, and in doing so, begin to realize the achievable goal of providing all people with an authentic opportunity to create a self-directed life.”

~ H/T to Norman Kunc

**Person-Centered Thinking**
Important TO & Important FOR

**IMPORTANT TO**
- happy, fulfilled, content, satisfied & comforted
- relationships – people to be with
- things to do and places to go
- rituals and routines
- status and control
- things to have
- rhythm or pace of life

**IMPORTANT FOR**
- health, safety and valued member of the community

**Health:**
- prevention
- treatment
- wellness

**Safety:**
- environment
- physical and emotional well being
- free from fear

In this video, the discovery of “important to” and “important for” and how to balance the two is demonstrated.
A Good Life

Service Life

Good Paid Life

Community Life

‘important for’ addressed

no organized effort to address

‘important to’

‘Important to’ recognized

‘to’ & ‘for’ present

closest people are paid & family

few real connections

‘Important to’ present

Focus on connecting, building relationships & natural supports

‘to’ & ‘for’ present

active circle of support

included in community life

A Good Life
**Systems Centered vs. Person Centered**

**System-Centered**
- plan a life time of programs
- offer a limited number of usually segregated programs
- relationships are unequal; people do things ‘for’ others
- risk is removed in order to keep people safe

**Person-Centered**
- create a desirable lifestyle
- community is seen as a rich resource of possibility
- relationships are reciprocal, give and take
- risk is acknowledged as a natural part of life
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.
The promise...

To create better lives not better paper.

- “listen” to all forms of communication
- focus on SPIN - Strengths, Preferences, Interests and Needs
- “peel the onion”
- think outside the box – challenge practices that separate people and perpetuate controlling relationships
- focus on actions, when words and actions are in conflict
- take action – to act on what a person tells us
- be honest – time, uncertainty, conflict
Person-Centered Planning - PCP

<table>
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<th>Benefits</th>
<th>Person-Centered Approaches</th>
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<td>• group process</td>
<td>• Charting the LIFECOURSE</td>
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<td>• changes the conversation</td>
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<td>• creates social connectedness</td>
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<td>• builds on strengths, gifts,</td>
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<td>talents, skills and</td>
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In this [video](#), Michael Smull explains what is meant by person-centered approaches, thinking and planning.
There is only one success…
to be able to spend your life in
your own way.

~ Christopher Morley
# Meaning and Principles

## Meaning

**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

**S.C.A.R.F.**

- support
- confirmation
- authority
- responsibility
- freedom
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.

~ American’s with Disabilities Act of 1990
Transition Services are a coordinated set of activities that help a student transition from school to adulthood.

Section 300.43: Transition Services
Transition Services

“Coordinated Set of Activities”

a broad accounting of...

- **what** will happen (activity)
- **when** it will occur (timeline)
- **who** is involved in each activity
- **who** is responsible (for providing and paying for the service)

Areas of Coordination

- instruction
- related services
- community experiences
- employment
- post-school adult living
- daily living skills (ADL)
- role of outside agencies

Texas Project First: [Coordinated Set of Activities](#)

Area of Coordination definitions available [here](#).
Health Care Transition

Health Care Transition...

It has been suggested that preparation for the pediatric to adult health care transition should start by the time the patient is 12-14 yoa. While it often receives less attention that other transitions (such as post-secondary education, employment, and independent living) it is equally important. The earlier you start, the more time you'll have to plan, and the more prepared you and your child will both be in the long run.
Transition Services in the IEP...

- start at age 14
- consider all aspects of adult life
- should focus on the students SPIN
- must be based upon completed, age appropriate, transition assessments
- include coordinated, measurable, annual, postsecondary goals
- include transition services (including courses of study) needed to assist the student in reaching those goals
- address decision-making skills that foster independence and self-determination, including a supported decision making agreement
- can include outside agencies
- provide notice of Transfer of Rights
- determine method of graduation
- provide a Summary of Performance
Healthcare Transition Resources

Care Notebooks

- Cook Children's Health Care Notebook
- Texas Parent to Parent (TxP2P) – Care Notebook

Healthcare Transition Guides

- ASAN – Transition to Adulthood: A Health Care Guide for Youth and Families
- Got Transition® – A Family Toolkit: Pediatric-to-Adult Health Care Transition
- Transition Checklist for Teens

Prescription Assistance Programs

- Good Rx
- Navigate Life Texas – Prescription Assistance

Extending Health Insurance: What You Need to Know - Texas Council for Developmental Disabilities
Thank You!