The Future is Coming: What’s In Your Toolbox?

2016 Health Disparities Conference
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A Look Ahead Series
www.alookaheadseries.com
Goal for Today

Provide participants information and links to resources (tools) needed to help plan a meaningful life for a person with a disability.

“There is only one success – to be able to spend your life in your **OWN** way.”

~ Christopher Morley ~
What’s in Your Tool Box?

• Assistive Technology
• Employment
• Guardianship & Alternatives to Guardianship
• Health Care Transition (Pediatric to Adult Care)
• Health Insurance Premium Payment (HIPP)
• Housing
• **IDD Services & Supports**
• Natural Supports
• **Person-Centered Planning**
• Post-Secondary Education
• Prescription Assistance Programs
• Puberty & Sexuality
• Self-Determination
• SSI
• State P&A (Disability Rights Texas)
• Texas Benefit Programs
• Transition Planning
Where to start?

Look Ahead... create a vision for the future
What do you believe?

1. I believe all people can learn
2. I believe all people can communicate
3. I believe all people can contribute to society
4. I believe all people can live independently
5. I believe all people can live a self-determined life
6. I believe all people can work
... disability is a natural part of the human experience and in no way diminishes the right of individuals to —

(A) live independently;
(B) enjoy self-determination;
(C) make choices;
(D) contribute to society;
(E) pursue meaningful careers; and
(F) enjoy full inclusion and integration in the economic, political, social, cultural, and educational mainstream of American society

— Developmental Disabilities Assistance and Bill of Rights Act (DD Act) —
What’s the **vision**?

- What do you want for your child **now** and in the **future**?
- What’s your **dream**?
- What’s their **dream**?
- What’s the **nightmare**?
Person-Centered Planning

PCP is an ongoing discovery process that leads to finding the balance between what **is important** to a person and **for** a person.

- uses a variety of skills and strategies
- encourages people to listen with all senses
- develops an action oriented plan
- changes lives
considers all aspects of life – live, work, play, pray, learn

challenges practices that separate people and perpetuate controlling relationships

identifies paid & natural supports

creates a plan of action
Person-Centered Planning can move you (and your child) from the paralysis of fear to an action-oriented plan with hopes and dreams for the future.

~ Texas Project First
Generally speaking…

• each program will have different eligibility requirements, rules, funding amounts, service options and service rates

• eligibility is determined when services are offered

• may not consider family income

• often require a lengthy wait to access
Service Options

• Adaptive Aids
• Behavioral Support
• Case Management
• Day Habilitation
• Dental Treatment
• Employment Assistance
• Medical Supplies
• Minor Home Modifications
• Nursing
• Residential Assistance
• Respite
• Specialized Therapies
• Supported Employment
• Vocational Training

"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
Community First Choice (CFC)

• available to Medicaid recipients with an institutional level of care

• service options included:
  – Personal Assistant Services
  – Emergency Response Services
  – Habilitation Services
  – Support Management Services

http://www.hhsc.state.tx.us/medicaid/managed-care/community-first-choice/
General Revenue (GR) Funded Services

• are state funded

• are primarily intended to help people remain in their own or their family's home

• are provided through a Local Intellectual and Developmental Disability Authority (LIDDA)

• service options can vary across the state
Medicaid ICF/IID Program
Intermediate Care Facility for Individuals with an Intellectual Disability of Related Condition

• 24 hour residential setting for people with IDD or related conditions

• facility serves 6 to several hundred people

• 2 ICF/IID models in Texas
  - State Supported Living Center (SSLC)
  - Community-Based ICF/IID
Targeted HCS Diversion Vacancy

The Texas Department of Aging and Disability Services (DADS) may make available a Targeted HCS waiver slot to an individual with an intellectual disability who is determined to be at imminent risk of admission to a State Supported Living Center (SSLC).

DADS protocol for requesting a Targeted HCS Diversion Vacancy

BLOG: Diversion Slots, A Way Off HCS Waiting List
Medicaid ICF/IID Waiver Programs

Provides services and supports to individuals with an Intellectual Disability (ID) or related condition who live in their own home, family home or other home-like setting.

- Waiver programs
  - Community Living Assistance and Support Services (CLASS)
  - Deaf/Blind Multiple Disabilities (DBMD)
  - Home and Community-based (HCS)
  - Texas Home Living Program (TxHmL)

- wait list for services

- funding moves with the person

- offers Consumer Directed Service (CDS) for some service options
Assistive Technology Act of 1998 (ATA) provides the following definitions...

- **AT Device**: Any item, piece of equipment, or product system, whether acquired commercially off-the-shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities.

- **AT Service**: Any service that directly assists an individual with a disability in the selection, acquisition, or use of an assistive technology device.
Intended Benefits

Any technology that enables someone to do something they otherwise couldn’t facilitates access and the opportunity to achieve a task previously determined unreachable. It provides new ways to...

- communicate
- receive instruction
- learn
- demonstrate understanding
- work
- play
- control the environment
- accomplish day-to-day activities
- move about and more...

AT provides access to and enhances all aspects of life; education, communication, leisure, employment, day-to-day activities and more.

Unintended Benefits

- increased independence, self-confidence and self-esteem
- participation in everyday life
Employment Strategies & Resources

- Customized Employment
- Integrated Employment
- Self-Employment & Entrepreneurship
- Supported Employment

Let’s Get to Work!
Integrated Employment

Integrated employment refers to jobs held by people with the greatest support needs in typical workplace settings where the majority of persons employed are not persons with disabilities. In these jobs, the individuals with disabilities earn wages consistent with wages paid workers without disabilities in the community performing the same or similar work; the individuals earn at least minimum wage, and they are paid directly by the employer.

http://www.dol.gov/odep/topics/IntegratedEmployment.htm
Customized Employment (CE)
CE helps people obtain integrated, competitive employment. This flexible process is designed to personalize the employment relationship between a job candidate and an employer in a way that meets the needs of both. It is based on an individualized match between the strengths, conditions, and interests of a job candidate and the identified business needs of an employer.
http://www.dol.gov/odep/topics/CustomizedEmployment.htm

Supported Employment (SE)
SE is a service that helps people maintain competitive, integrated employment.
Guardianship & Alternatives

- Guardianship is a legal process
- Guardianship does two things
  1) Removes certain rights and privileges from the “ward” (person determined to be incapacitated)
  2) Creates a three party relationship between the person with a disability, their family and the government
The majority of people with intellectual and developmental disabilities can manage their own affairs with informal assistance and guidance from family, friends, and others.
Got Transition? Center for Health Care Transition
a national resource focusing on a young adult's transition from pediatric
to adult health care. This site serves as the basis for an information
exchange about health care transition, particularly as pertaining to
youth with special health care needs.
http://gottransition.org/about/index.cfm

Baylor College of Medicine and Texas Children’s Hospital’s Annual
Chronic Illness & Disability Conference: "Transition from Pediatric to
Adult-based Care“ (October 27-28, 2016)
http://www.baylorcme.org/search/detail.cfm?cme=1001

Smooth Moves Youth Health Transition (YHT)
Smooth Moves YHT is a health information site created to help teens
navigate the move to adulthood.
https://www.smoothmovesyht.org/
Health Insurance Premium Payment (HIPP)

HIPP is for families who:

- have at least one person who gets Medicaid
  AND
- can get Employer-Sponsored Insurance through a family member’s work

How Does HIPP Work?

- annual application process
- Medicaid pays your family’s Employer-Sponsored Insurance costs

http://gethipptexas.com/
Housing Options

- Host Family Home through the HCS Waiver program
- Cooperative Housing
- Family Home
- Home & Community-Based Services (HCS) Group Home
- Home, Apartment, Condominium, Duplex, and Townhome Rental or Ownership
- Intermediate Care Facility for Individuals with an Intellectual Disability - (ICF/IID)
  — Community ICF/IIC Group Home
  — State Supported Living Center (SSLC)
- Residential/Vocational Community
Natural Supports

Natural supports refer to the support and assistance that naturally flows from the associations and relationships typically developed in natural environments such as the family, school, work and community.

The quality of your **LIFE** is the quality of your **RELATIONSHIPS**!

Navigate Life Texas Blog: Natural Supports
https://www.navigatelifetexas.org/en/blog/article/natural-supports
Why access Natural Supports?

• they are already there

• promote feelings of **belonging** and participation in every day **LIFE**

• form **real** relationships

• are not dependent on “funding” or “eligibility”

• offer a wider range of opportunities
Post Secondary Education
(education after high school)

Receiving a post-secondary education (education after high school) and experiencing that very exciting time in life is as beneficial for students with intellectual and developmental disabilities as for students without.

Post Secondary options *(there are more)*

- Community classes (rec. center, retail store, fine arts, etc.)
- College (for credit classes, continued learning, auditing a class)
- Specialized College programs
- Trade School
Prescription Assistance Programs

RxAssist
RxAssist offers a comprehensive database of patient assistance programs, as well as practical tools, news, and articles so that health care professionals and patients can find the information they need. All in one place.

http://rxassist.org/

Texas Drug Card
The Texas Drug Card Program is a FREE statewide Rx assistance program available to all Texas residents

http://texasdrugcard.com/index.php
Puberty & Sexuality

Navigate Life Texas: Puberty & Sexuality

NLT is a web-based resource created by and for families of children with disabilities. In this section you will find tips, articles and resources available to help you talk with your child.


• Get comfortable talking about these issues – use proper terminology

• Lack of knowledge = increased risk of abuse, exploitation and potential criminal behavior

• Answer questions – if you don’t someone else will
Self-determination is an individual’s right to make choices about their own lives, to have the same rights and responsibilities as everyone else, and to speak and advocate for themselves.

The 5 Principles of Self-Determination

- **Freedom**… to decide how one wants to live his or her life
- **Authority**… over resources
- **Support**… to organize resources in a way that are life enhancing and meaningful to the person
- **Responsibility**… for the wise use of public dollars and the recognition of the contributions individuals make in their community
- **Confirmation**… individuals should play an important leadership role in a newly designed system
"The quality of my life is related to how free I am to make my own choices."

- Ed Roberts
Self-Determination & Adult Outcomes

• higher quality of life

• more positive post-secondary outcomes – including employment, independent living and community inclusion

• more independent one year after graduation

Self-Determination and People with Disabilities: What Does the Research Tell Us?
http://www.aucd.org/docs/SD-WhatDoWeKnow.pdf
The Dignity of Risk

a comfort zone

is a beautiful place,

but nothing

ever grows there.

- Unknown
Federally designated legal protection and advocacy agency (P&A) for people with disabilities in Texas.

- 6 regional offices across the state
- Service priorities are re-established every 4 years and reviewed annually by the Board of Directors

http://www.disabilityrightstx.org/
Texas Benefit Programs

• **Comprehensive Energy Assistance Program (CEAP)** — is designed to assist low income households in meeting their immediate energy needs and to encourage consumers to control energy costs through energy education.  
  [http://www.tdhca.state.tx.us/community-affairs/ceap/index.htm](http://www.tdhca.state.tx.us/community-affairs/ceap/index.htm)

• **SNAP** — Texas Food Stamp Program  
  [https://yourtexasbenefits.hhsc.texas.gov/programs/snap/](https://yourtexasbenefits.hhsc.texas.gov/programs/snap/)

• **Weatherization Assistance Program (WAP)** — provides free of cost weatherization services to income eligible households in Texas. Weatherization services reduce fuel dependency and make homes more energy efficient.  
STAR + PLUS

- STAR+PLUS is a Texas Medicaid managed care program for people who have a disability or are age 65 or older.

- People in STAR+PLUS get basic medical services (doctor visits, hospital visits and medication) and long-term services and supports, and service coordination through a medical plan that they choose.

http://www.hhsc.state.tx.us/medicaid/managed-care/starplus/
Supplemental Security Income (SSI)

- designed to help those who are aged, blind, or have disability (a physical or mental condition) so involved that it prevents working substantially for at least 12 months

- provides a monthly check for basic needs (food, shelter, clothing) and Medicaid

Tips

- Keep good records – Dr. appointments, medications, hospitalizations, diagnosis, assessments, school records, etc...

- Provide ALL information
Texas Department of State Health Services

- provide mental health services for children and adults

- contract with 37 Local Mental Health Authorities (LMHA) often co-located with a LIDDA

- operate a referral line 24 hours a day 7 days a week

http://www.dshs.state.tx.us/MHSA/
Transition Services

Transition services means a coordinated set of activities for a student with a disability that

- are designed to be within a results-oriented process that facilitates movement from the school to post-school activities, including
  - Postsecondary education
  - Vocational education
  - Integrated employment (including supported employment)
  - Continuing and adult education
  - Adult services
  - Independent living
  - Community Participation
The coordinated set of activities **MUST** be based on the *individual student’s needs*, taking into account the student’s strengths, preferences, and interests and include the following:

- Instruction
- Related services
- Community experiences
- Development of employment and other post-school adult living objectives
- The acquisition of daily living skills and provision of a functional vocational evaluation, when appropriate.
Transition Planning...

- by age 16 or younger if determined appropriate
- includes student involvement
- assists in planning the middle/high experience
- explores possibilities and identifies goals
- encourages collaboration
- help students and families make community and adult agency connections

transition planning should begin at diagnosis
Next Steps

• Get organized

• Request records you don’t have — IEP paperwork, assessments, diagnostic testing, hospitalizations, etc.

• Continue learning — conferences, workshops, internet, parent groups

• Develop a vision — the future is for you and your child to create

• Start Planning — it’s never too early and it’s never too late to start planning