Resources to create a meaningful life for your child

Empowering individuals with IDD and their families to live life as they define it.

www.arcgmc.org info@arcgmc.org

Advocacy – Awareness – Training – Support

Goal for Today

Explore topics & resources to help plan a meaningful life for a person with a disability.

Where will my child...

• Live
• Learn
• Work
• Play
• Worship

• What supports make life possible
• Who will be the decision maker
There is nothing more dangerous than an educated parent with options.

... disability is a natural part of the human experience and in no way diminishes the right of individuals to —

live independently;
enjoy self-determination;
make choices;
contribute to society;
pursue meaningful careers; and
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 do you believe?

1. I believe all people can communicate
2. I believe all people can learn
3. I believe all people can contribute to society
4. I believe all people can live a self-determined life
5. I believe all people can live independently
6. I believe all people can work
Independence OR Interdependence

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.

What's the VISION?

What do you want for your child now and in the future — your dream?
What's your nightmare?
What do they want for themselves?
How do YOU define your role in helping your child reach their goals?
Who can help you to help your child reach their goals?

CLEAR VISION CLEAR RESULTS

Person-Centered Planning can move you (and your child) from the paralysis of fear of the unknown to an action-oriented plan with HOPES and DREAMS for the future.
Creating a vision brings the future into the present so you can do something about it TODAY!

The future is... coming, and will be here before you know it for you and your child to create doesn’t have to be based on what others think possible or have done before you.

Let not our needs determine our dreams... but let our dreams determine our needs.

c. tomko

**SSI/Medicaid**

- based on financial need – must meet eligibility requirements
- Medicaid = basic health insurance
- SSI automatically comes with Medicaid
- receive a monthly check for basic needs – food, shelter, clothing
- to receive the full amount declare your child will pay their “fair share”
- Compassionate Allowances (CAL)

**How to Apply**

*Online*

https://yourtexasbenefits.com/learn/home

or

https://www.ssa.gov/disability/

*Call*

211
1-800-772-1213
TTY 1-800-325-0778

https://www.ssa.gov/special-help/compassionate

https://www.ssa.gov/ssi

**Health Insurance Premium Payment (HIPPP)**

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
- proof of premium payment submitted monthly
- Medicaid pays your family’s Employer-Sponsored Insurance premium amount
- HIPP pays co-pays and deductibles when people with HIPP and Medicaid see a Medicaid doctor

http://gethipptexas.com/
Community First Choice (CFC)

CFC provides certain services and supports to individuals living in the community who are enrolled in the Medicaid program and meet CFC eligibility requirements.

**CFC Eligibility**
- Enrolled in Medicaid, including individuals served by...
  - 1915 (c) waiver programs;
  - Medicaid managed care; and
  - personal care services for children.

**CFC Services**
- emergency response
- habilitation
- personal assistance
- support management


General Revenue Services

GR services (aka as IDD Community Services) are provided by or through the Local IDD Authority (LIDDA) and are primarily intended to help people remain in their own or family home.

**GR Eligibility**
- Must meet one of the following...
  - Intellectual Disability Diagnosis
  - Autism Diagnosis
  - Eligible for ECI Services
  - NF resident eligible for specialized services for IDD or a related condition

**GR Services**
- behavioral supports
- community support
- day habilitation
- employment assistance
- nursing
- respite
- specialized therapies
- supported employment
- vocational training

**NOTE:** Services may vary by location


Long-Term Services & Supports (LTSS) Medicaid Waiver Programs

**LTSS Medicaid Waiver Programs**
- Waives off Nursing Facility (NF)
  - CLASS
  - DBMD
  - STAR+PLUS HCBS (call 1-855-937-2372)
- Waives off Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID)
  - Contact your LIDDA (Local IDD Authority)
  - HCS
  - MDCP (children less than 21 years of age)
  - Tex Haw (considers family income)

**Generally Speaking**
- each program has different eligibility requirements, service options and service rates
- services assist people of all ages to live in the community instead of an institution
- access most often requires a lengthy wait for services (up to 13+ years) – over 100,000 people are waiting
- eligibility determined when services are offered
- funding moves with the person

Service options may include but are not limited to:

- Adaptive Aids
- Audiology
- Cognitive Rehabilitation Therapy
- Community Support Services
- Day Habilitation
- Dental Treatment
- Dietary
- Employment Assistance
- Financial Management Services
- High Medical Needs Support
- High Medical Needs Support LVN
- High Medical Needs Support RN
- Home Host/Companion Care
- Minor Home Modification
- Nursing
- OT, PT, ST & Specialized Therapies
- Prescribed Drugs
- Residential Support Services
- Respite
- Supervised Living
- Support Consultation
- Supported Employment
- Supported Home Living
- Transportation

and more...

[Link to more information](https://hhs.texas.gov/sites/hhs/files/documents/doing-business-with-hhs/providers/resources/ltss-waivers.pdf)

**Medicaid ICF/IID Services**

An Intermediate Care Facilities for Individuals with an Intellectual Disability or Related Conditions (ICF/IID) is a 24-hour institution-based residential care setting.

<table>
<thead>
<tr>
<th>Community-based ICF/IID</th>
<th>State Supported Living Center (SSLC)</th>
</tr>
</thead>
<tbody>
<tr>
<td>the number of people served can range from 6 to several hundred</td>
<td>state operated facilities</td>
</tr>
<tr>
<td>owner/operator can determine additional admission criteria</td>
<td>13 Centers across the state</td>
</tr>
<tr>
<td>owner/operator can deny admission</td>
<td>Mexia SSLC primarily serves alleged offenders</td>
</tr>
<tr>
<td>there are 815 Community-based ICF/IID facilities in Texas</td>
<td>declining population</td>
</tr>
<tr>
<td>funding is tied to the facility</td>
<td>DOJ OCR sued Texas and entered into a settlement agreement with the state in 2009 due to: serious deficiencies at multiple facilities, a long history of ANE, and failure to serve Facility residents in the most integrated setting appropriate to their individual needs</td>
</tr>
</tbody>
</table>


**Star + Plus**

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

- 21 years of age or older
- have a mental or physical disability and qualify for Medicaid
- services provided through a Managed Care Organization
- medical and long-term services
  - Day Activity and Health Services (DAHS)
  - Primary Home Care (PHC)
- service coordination
- value-added services

[Link to more information](https://hhs.texas.gov/services/health/medicaid-chip/programs/starplus)
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) and who qualifies as a member of the Targeted Diversion Slot Group.

Protocol for offering Targeted HCS Diversion Vacancy

BLOG: Diversion Slots, A Way Off HCS Waiting List

DisabilityRights Texas
federally designated legal protection and advocacy (P&A) agency
focused priorities established every 4 years
statewide intake line
1-800-252-9108
24/7 online intake
https://www.intake.drtx.org
https://www.disabilityrightstx.org/

help for older adults and people with disabilities
key point of access to LTSS programs, information & community resources
1-855-937-2372

TX DSHS Mental Health Services

DSHS Children’s Mental Health serves children ages 3 through 17 with a diagnosis of mental illness (excluding a single diagnosis of substance abuse, intellectual disability, autism or PDD) who exhibit serious emotional, behavioral or mental disorders and who:

- have a serious functional impairment; or
- are at risk of disruption of a preferred living or child care environment due to psychiatric symptoms; or
- are enrolled in a school system’s special education program because of serious emotional disturbance.

http://www.dshs.texas.gov/mhsa/mh-child-adolescent-services/
TX DSHS Mental Health Services

DSHS Adult Mental Health

Services are provided by 37 Local Mental Health Authorities (LMHA) often co-located with a Local IDD Authority (LIDDA)

Offer an array of services

Services option may vary by location

Operate a Crisis Line 24 hours a day, 365 days a year

http://www.dshs.texas.gov/mhssa/mh-child-adolescent-services/

Natural Supports

Natural supports refers 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.

**Benefits**

- Can be accessed for fun, encouragement or assistance
- Are not dependent on “funding” or “eligibility”
- Promotes feelings of belonging and participation in life
- Offers a wide range of opportunities

**TIPS**

- Change the conversation
- Don’t limit options to specialized programs
- Resist the isolation
- Think long-term – LIFE is your program
- Be patient - don’t give up

Assistive Technology (AT)

AT, also referred to as Adaptive Aids, provide access to and enhance all aspects of life; communication, day-to-day activities, education, employment, leisure and more.

**Assistive Technology 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.

**Assistive Technology service:** any service that directly assists an individual with a disability in the selection, acquisition, or use of an assistive technology service.
For people without disabilities, technology makes life easier. For people with disabilities, technology makes life possible!

AbleData.com
http://www.abledata.com

Center on Technology and Disability (CTD)
http://ctdinstitute.org/

International Society of Augmentative and Alternative Communication (ISAAC)
http://www.isaac-online.org/english/home/

Specialized Telecommunications Assistance Program (STAP)
http://hhs.texas.gov/services/disability/deaf-hard-hearing/specialized-telecommunications-assistance-program-stap

Texas Technology Access Program (TTAP)
http://techaccess.edb.utexas.edu/

Employment?
Let's Get to Work!

Customized Employment is a flexible process designed to personalize the Employment relationship between a job candidate and an employer in a way that meets the needs of both.

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.

Self-Employment & Entrepreneurship

Supported Employment is a service that helps people maintain competitive, integrated employment.

True or False?

1. A working person with a disability can legally be paid wage rates less than the Federal minimum wage.

2. A person with a disability will lose their benefits if they work.

Association for People Supporting EmploymentFirst - (ASPE)
http://www.apse.org/

DADS Employment First Initiative
https://hhs.texas.gov/services/disability/employment/employment-first

JAN – Job Accommodation Network
http://jobjan.org/

Project SEARCH
http://www.projectsearch.us/Home.aspx

SSI Work Incentive Programs for SSI & SSDI Beneficiaries
http://www.issa.gov/disabilityresearch/vr/generalinfo.html#ssiwi

Texas Workforce Commission (TWC) Vocational Rehabilitation (VR) Services
http://www.twc.state.tx.us/jobseekers/vocational-rehabilitation-services

UNT WISE (Workplace Inclusion and Sustainable Employment)
http://wise.unt.edu/

U.S. Department of Labor (DOL) Office of Disability Employment Policy (ODEP)
http://www.dol.gov/odep/
**Decision Making**

**Guardianship**
- A legal process
- 2 types: guardian of the person and/or guardian of the estate
- Removes some or all of a person's decision making rights
- Creates a three-party relationship between the person with a disability, their family, and the courts - requires annual accounting and reports on the condition of the “ward”

**Alternatives to Guardianship**

**True or False?**

1. Parents of an adult child (18+) will be unable to attend their child's ARD/IEP meeting or make decisions at the meeting unless they have legally obtained guardianship.

2. A parent can not talk with their child's medical team unless they have legally obtained guardianship.

**Self-Determination**
- Values choice & ownership – making decisions and being in charge of your own life, but not necessarily the same thing as independence or self-sufficiency
- Will look different for each person
- Begins in childhood and continues throughout one's life
- Based on 5 principles
  - Authority
  - Freedom
  - Responsibility
  - Support
  - Confirmation
- Recognizes the dignity of risk – the ability to succeed and fail with grace
I'm Determined
http://www.imdetermined.org/

National Center for Secondary Education and Transition Research to Practice Brief
Self-Determination: Supporting Successful Transition
http://www.ncset.org/publications/view.asp?id=962

The Center for Self-Determination
http://www.centerforselfdetermination.com/

The Self-Determination Group
http://www.facebook.com/TheSelfDeterminationGroup-715920048445004/

A Place Called Home

- co-housing
- family consortium
- family home
- HCS group home
- host home
- ICF/IID (2 types in Texas)
- own home
- privately funded communities
- Section 8 Housing

Community for Permanent and Supportive Housing (CPSH)
http://www.cpshtx.org/

Fair Housing Act

Olmstead Decision
1999 U.S. Supreme Court Decision
https://www.ada.gov/olmstead/olmstead_about.htm

Texas Department of Housing and Community Affairs (TDHCA) Programs
affordable housing, barrier removal and energy assistance programs & assistance in leaving an institution
http://www.tdhca.state.tx.us/

What does your child’s future home look like? Will they live alone or with a roommate?

Co-housing
an intentional community of private homes clustered around shared space
http://www.cohousing.org/

Family Consortium
- small group of parents pool resources to manage a home for their children
- parents work closely together
- may buy or rent a house/condo/apartment
- manage support services together

HCS Group Home
- service option through the Home & Community-based Services Waiver program – long wait
- maximum of 4 residents

ICF/IID
- institution-based model of care
- 2 types in Texas
  - community-based
  - State Supported Living Center (SSLC)

Texas Department of Housing and Community Affairs (TDHCA) Programs
affordable housing, barrier removal and energy assistance programs & assistance in leaving an institution
http://www.tdhca.state.tx.us/
Privately Funded Communities
- residential-vocational community
- admissions application process
- not funded by Medicaid waiver services

Section 8 Housing
- Housing Choice Section 8 Housing Voucher
  - provides rental assistance
  - independent – direct negotiations
  - approved rental amounts paid directly to landlord

IDEA PURPOSE
...to ensure students with disabilities have access to a “free appropriate public education” that emphasizes special education and related services designed to meet their unique needs and to prepare students for further education, employment and independent living.

Free – "without charge" to parents or children
Appropriate – "in keeping with an individual education plan"
Public – "at public expense, under public supervision and direction"
Education – "preschool, elementary or secondary school..."

Online Resources
- Texas Project First
- The Legal Framework for the Child Centered Special Education Process
- Wrightslaw
- Your Special Education Rights

Publications
- Notice of Procedural Safeguards
  [http://framework.esc18.net/Documents/Pro_Safeguards_ENG.pdf](http://framework.esc18.net/Documents/Pro_Safeguards_ENG.pdf)
- Parents Guide to the ARD Process
- Special Education Rules & Regulations Side by Side
- The IDEA Manual
  [http://www.thearcoftexas.org/idea-manual/]

*All publications can be downloaded for FREE*
Inclusive Education

- Training
  - Arc Texas: Annual Inclusion Works! Conference
    https://www.thearcoftexas.org/
  - Arc Greater Mid Cities: Creating *IEPs Annual Conference
    (*Informed, Empowered Parents)
    http://www.arcgmc.org/creating-ieps.html
  - Education Service Centers (ESC)
    http://tea.texas.gov/regional_services/esc/
  - Partners Resource Network
    http://prntexas.org/

- Planning Tools
  - ARD/IEP Meeting Agenda
    following an agenda helps the IEP team plan special education services for a student using a step-by-step process
    http://texasprojectfirst.org/node/8
  - Planning Matrix
    used to determine where a child may best meet their goals
    http://texasprojectfirst.org/node/175
  - Prior Written Notice (PWN)
    a written explanation as to why the school refused a parent request
    http://www.wrightslaw.com/info/pwn.refusal.martin.htm

- Inclusive Education
  - research, thought-provoking articles, tips, tools & guidance & videos
    http://www.arcgmc.org/inclusive-education.html

Post-Secondary Education

- OPTIONS
  - community classes
  - recreation center, retail store, fine arts and others
  - college
  - for credit classes, continued education classes, auditing a class
  - specialized college programs
  - trade school

- HEATH Resource Center Clearinghouse
  http://www.heath.gwu.edu/
- National Center on Secondary Education and Transition (NCSET)
  http://www.ncwd-youth.info/topic
- Think College
  http://www.thinkcollege.net/

Online Resources

- Navigate Life Texas
  - written by families
  - information articles
  - searchable resources
  - local & statewide events
  - videos
  - blog posts
  - https://www.navigatefortexas.org/en
### Ready, Set, Go!

<table>
<thead>
<tr>
<th>What I learned</th>
<th>What I need to know more about</th>
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<tbody>
<tr>
<td>create a vision</td>
<td>create diagnostic paperwork, assessments, IEP paperwork, helpful people &amp; organizations, find your tribe</td>
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<tr>
<td>let the vision guide you</td>
<td>diagnose paperwork, assessments, IEP paperwork, helpful people &amp; organizations, find your tribe</td>
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<td>decisions &amp; actions</td>
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<td>learn from mistakes</td>
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<td>allow for creativity and flexibility</td>
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