



# **Webinar 2: Nuts and Bolts of Family Future Planning**

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**Katie Arnold**  
**University of Illinois Chicago**

The background of the slide features a large, dark silhouette of a tree on the left side. Below the tree, there are silhouettes of several children playing. One child is in a dynamic pose, possibly jumping or kicking. To the right, another child is leaning forward. Further right, a girl in a dress is walking, and a child in a wheelchair is also visible. The entire scene is set against a light blue sky that transitions into a white circular area on the right side of the slide, which contains the text.

# Overview

- Areas of planning:
  - legal,
  - financial,
  - residential,
  - communication supports, and
  - building relationships and social support networks

# Katie's Siblings

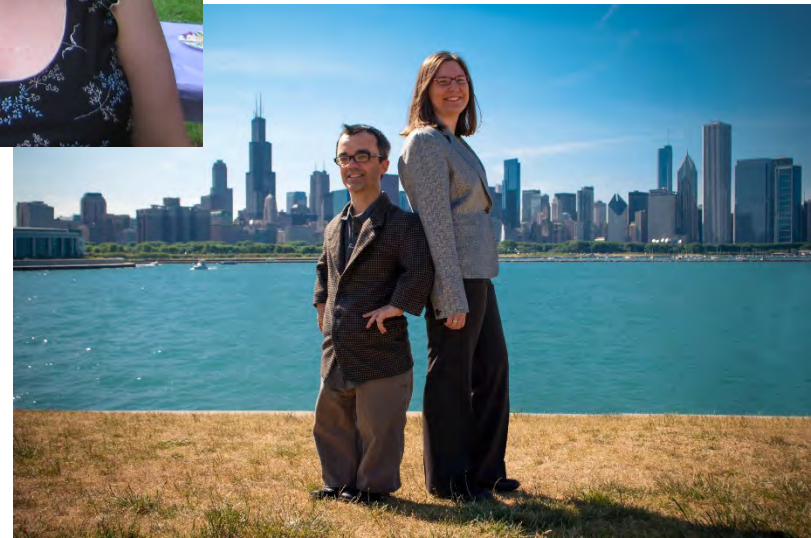




# Katie's Sibling Experience



- Learned to be an advocate at a young age
- All these skills have helped me well in my life





[www.siblingleadership.org](http://www.siblingleadership.org)

## Mission

To provide siblings of individuals with disabilities the information, support, and tools to advocate with their brothers and sisters and to promote the issues important to them and their entire families.



Texas Sibling Network:

<https://disabilitystudies.utexas.edu/TSN>

# Future Planning Research with Adults with IDD

- 10 adults with IDD and Key Support Persons interviewed
- Future Planning is the process of gathering information, discussing among the family, and making decisions about the future direction for the people with IDD
- Starting the difficult dialogue about the future is hard

*“We don’t want to think about it, but we have made preparations.”*

*-Ethan’s dad*



# Future Planning Research (cont.)

- A few families had experienced major life transitions
- Reality of mortality—what will happen when the primary caregiver is no longer there?

*“I tell him, we have to get ready for a world without me because I'm not always going to be here. And he doesn't want to hear it.”*

*-Nelson's mom*

- Legal and financial planning

*“it's a little bit of a source of stress for me because if he dies and it's left, it goes to the government. They take it.”*

*-Nick's mom*

- Living situations-families discussed potential living situations



# Siblings in Future Planning

- Siblings often become the next generation of supporters and caregivers
- Parents do not want to impact the lives of their children with future caregiver roles, yet they often have an expectation that siblings will take on a role when the time comes
- Families were at different places in terms of how much they had discussed future planning with siblings





# Katie's Family Future Planning Meetings



# Special Needs Trusts

- Setting up a special needs trust takes an initial financial investment, although in the long run it can also help save money.
- Special Needs Alliance:  
<http://www.specialneedsalliance.org/>



# ABLE Accounts

- ABLE = Achieving a Better Life Experience
- ABLE Accounts help people with disabilities have a savings account for money that is to supplement, but not supplant, other benefits a person without negatively impacting benefits.
- The Texas ABLE Program:  
<https://www.texasable.org/>



# Financial Planning

- **Social Security Disability Insurance (SSDI)** - monthly benefit paid to the person with disabilities based on their parent's Social Security earnings record.
- **Supplemental Security Income (SSI)** - benefits to disabled adults and children who have limited income and resources. This is based on financial need.
- **Medicaid** - provides health coverage to eligible low-income adults, children, pregnant women, and people who are older or who have disabilities. Many people with disabilities use Medicaid to access social and community supports, including housing supports and other long term services.
- **Medicare** - health insurance program for people age 65 or older or people younger with certain disabilities. The program helps with the cost of health care, but it does not cover all medical expenses or the cost of most long-term care.

**Your Texas Benefits:**

<https://www.yourtexasbenefits.com/Learn/Home>



# Decision-Making Supports



# Supported Decision-making

- A process of supporting an adult with disabilities to make his or her own decisions that fosters the person's self-determination and does not take away their rights.
- In 2015 Texas became the first state to put supported decision-making in law.

*Think about ways that you can support the person with disabilities to make decisions for themselves.*



# Supported Decision-making Resources



- Texas Council for Developmental Disabilities information:  
<http://www.tcdd.texas.gov/resources/guardianship-alternatives/supported-decision-making/>
- Texas Sibling Network video:  
<https://www.youtube.com/watch?v=nzAqoNWFafl>
- The Arc of Texas Fact Sheet:  
[https://www.thearcoftexas.org/wp-content/uploads/2016/06/Supported Decision Making For Families UPDATED Jan 2016.pdf](https://www.thearcoftexas.org/wp-content/uploads/2016/06/Supported_Decision_Making_For_Families_UPDATED_Jan_2016.pdf)
- Disability Rights Texas sample supported decision-making agreements: <https://www.disabilityrightstx.org/resources/supported-decision-making>

# Surrogate/Substitute Decision-making



- **Representative Payee** is an individual or organization that serves as a representative to help a person manage his or her government benefits.
- **Power of attorney** is when someone is given authority to make legal and financial decisions on a person's behalf
- **Health Care Surrogacy/Proxy** is a document that allows an individual to appoint someone to make health care decisions for them if they are or become unable to make these types of decisions by themselves.
- **Guardianship** is when someone is designated to make decisions on behalf of someone else. This should be the last option to consider because it can take away rights of people.



# Communication Support



*What ways could you help the person with disabilities think about and express their preferences and desires for the future?*

# Self-Advocacy

- Self-advocacy is about people with disabilities speaking up for themselves.
- Texas Advocates has 20 local chapters of self-advocacy groups across the state.

<http://www.texadvocates.org/about-us-2/>



*Is your family member with disabilities involved in a self-advocacy group? If not, how could you support your them to learn about and consider getting involved?*

# Person Centered-Planning



- A process of planning for the future that puts the person with disabilities at the center. The person brings together the important people in their life to focus on what they want for the future and discuss ways they can get support to reach their goals
- Institute for Person-Centered Practices:  
<http://www.person-centered-practices.org/about.html>

# Natural Supports

- Natural supports are unpaid supports in the community—friends, neighbors, community members can provide natural support.
- Natural supports don't always happen naturally!
- These are relationships that need to be nurtured intentionally.





# Building Support Networks



- When more people are invited into a person's life, just as more candles are lit, the light can grow and brighten the room way beyond the small corner of light that the family started out with.
- Expanding a person's social networks makes a difference beyond anything their own family could have done alone.

# Increasing Social Capital

can gain a collective benefit from expanding your social networks.



*Think about ways your family can use social capital, or your community connections and relationships to support your family member with disabilities to do more in the community and rely less on your family to make it happen. Write down ideas you have and bring them to your family to discuss.*

# Residential Planning



# Housing Resources



- For Home and Community Based supports and services for adults with intellectual disabilities, the Medicaid waiver in Texas provides residential services and a lot more: employment services, certain therapies, adaptive aids and more.
- Texas Health and Human Services: [hhs.texas.gov](https://www.hhs.texas.gov)
- Your Texas Benefits: [www.yourtexasbenefits.com](https://www.yourtexasbenefits.com)
- Meet with a benefits specialist to help you navigate the system to get the needed supports.



# Respite



- Respite is when you have someone else look after your loved one while you take a short break
- It can be provided in your home or a community location
- All people providing care for a loved one need and deserve a break at some point and it can help the person continue to provide great care and be beneficial to the person they are caring for and their whole family.
- Respite in TX:  
<https://apps.hhs.texas.gov/taketimetexas/what-is-respite.html>
- ARCH National Respite Network: [archrespite.org](http://archrespite.org)

# Centers for Independent Living



- CILs provide services to help learn independent living skills, get counseling to better understand their disability and help them reach their goals, enhance their advocacy skills, help people transitioning from institutional settings to community-based residences, find post-secondary education opportunities, and more.
- Find a Center for Independent Living near you: <https://hhs.texas.gov/services/disability/independent-living-services>

# “A Day in the Life”



Schedule  
Medicines  
Doctors  
Key contacts

Emergency  
Plan

# Katie's Family Future Planning Process





Everyone in the family should have a  
**voice and a choice** in the process



# Areas of Planning:

- Legal Planning
- Financial Planning
- Residential Planning
- Building Relationships and Support Networks



# Contact Information

► Katie Arnold

[kkeiling@uic.edu](mailto:kkeiling@uic.edu)

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