Preventing Crisis through Future Planning

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2023 Conference

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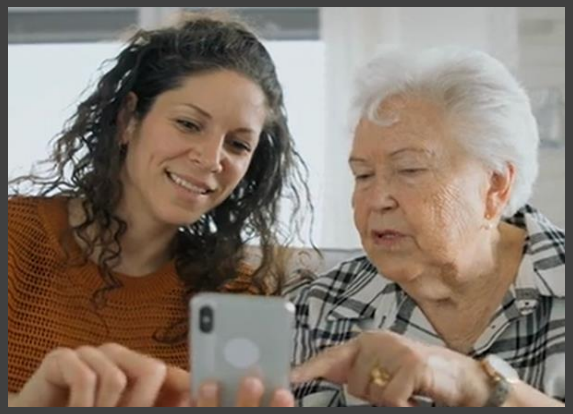
The Arc



METROPOLITAN GOVERNMENT • NASHVILLE AND DAVIDSON COUNTY •

Objectives

- Understand the need for Future Planning
- Understand the steps for Future Planning
- Understand Decision-Making Support options for Older Adults and Aging Caretakers of Persons with Disabilities
- Learn resources and tools to help families, caretakers and providers with Future Planning for Older Adults and Person with Disabilities.

Aging Population Growth

- The number of Tennesseans ages 60 and older is projected to grow from an estimated 1.66 million in 2021 to over 1.92 in 2030**
  - By 2030, 25% of Tennessee's population will be 60 or older. †
  - 38% of Adults 60+ have a disability (est. 631,791) †
  - 12% of Older Tennesseans live below poverty (est. 199,513) **

- Medicare enrollees 65+ (est. 1,047,188) - 42% have 4+ Chronic conditions (est. 439,818) **

TCAD, Tennessee State Plan on Aging 10/1/2017-9/30/2021
***2022 Tennessee STATE AGING PROFILE*
† TN State website

Aging Caretaker Growth

- More than 70% of adults with developmental disabilities live at home with family caregivers, and of this group * …
  - 25 % live with family caregivers who are age 60 years or older.*
  - It is estimated that 18,991 Tennesseans lived with aging caregivers in 2013.*
- 33,420 Grandparents were raising their grandchildren (2022)**

*TCAD, Tennessee State Plan on Aging 10/1/2017-9/30/2021
** Tennessee STATE AGING PROFILE

Ready for the Aging Years?

With this growth in the Aging population there is an increased need to prepare for their basic needs, medical and financial needs, and any end-of-life support services?

The key question is…**Are they ready?**

- Do they have a plan in place?
- Do they have someone to execute that plan?
- Do they have the financial capacity to support their plan?
- Do they know how or where to start?

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Future Planning: The Need

What is Future Planning?

*The process of creating a guide (plan) for a person with a disability (and an aging adult) to lead a good life as independently as possible.**

- Should cover all life stages and/or life domains.
- Should be unique to the person's needs.
- Should be updated yearly or as appropriate.
- Should be accessible to those who may need to use it.
- Person with a disability should be included to help develop the plan, to the extent he/she is capable.

**The Arc Center for Future Planning*
https://futureplanning.thearc.org/pages/learn/future-planning-101

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Need for Future Planning

- Aging population growth.
- Need for surrogate decision-makers for the aging adults and aging caretakers.
- Burden on the healthcare and court systems to find surrogate decision-makers.
- Burden on support systems and provider staff to provide adequate care.
- Individual's quality of life may be impacted.
- Limited resources to cover needed supports and services.
- More??

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Future Planning Starts Now

It is never too soon to prepare for the future.

- Anyone could have an emergency or develop a medical condition that could render them incapacitated.
- What happens to the person with a disability whose caregiver becomes incapacitated or deceased?
- What happens to the caregiver that becomes incapacitated?
- Future planning can prevent or minimize a crisis situation by having a plan of action in place.

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Types of Future Planning

- Planning for an aging person with dementia or other disabilities.
- Planning for short-term and long-term care of the person with a disability.
  - With the primary caretaker in place.
  - When the primary caretaker is no longer able to care for the person with a disability.
  - Includes transitions
- Planning for the primary caretaker.
  - When the caretaker can no longer take care of the person with a disability due to the caretaker's incapacity.

Barriers to Future Planning

Anxiety about mortality – just don't want to think about it

Unaware of options – legal and financial

Unaware of possibilities and resources

Lack of resources and knowledge

Afraid to "burden" siblings – reluctance to include siblings in planning

Restricted social network/natural supports

Lack of collaboration between aging and disability services systems

Too Overwhelming … Just need Help

Steps for Future Planning

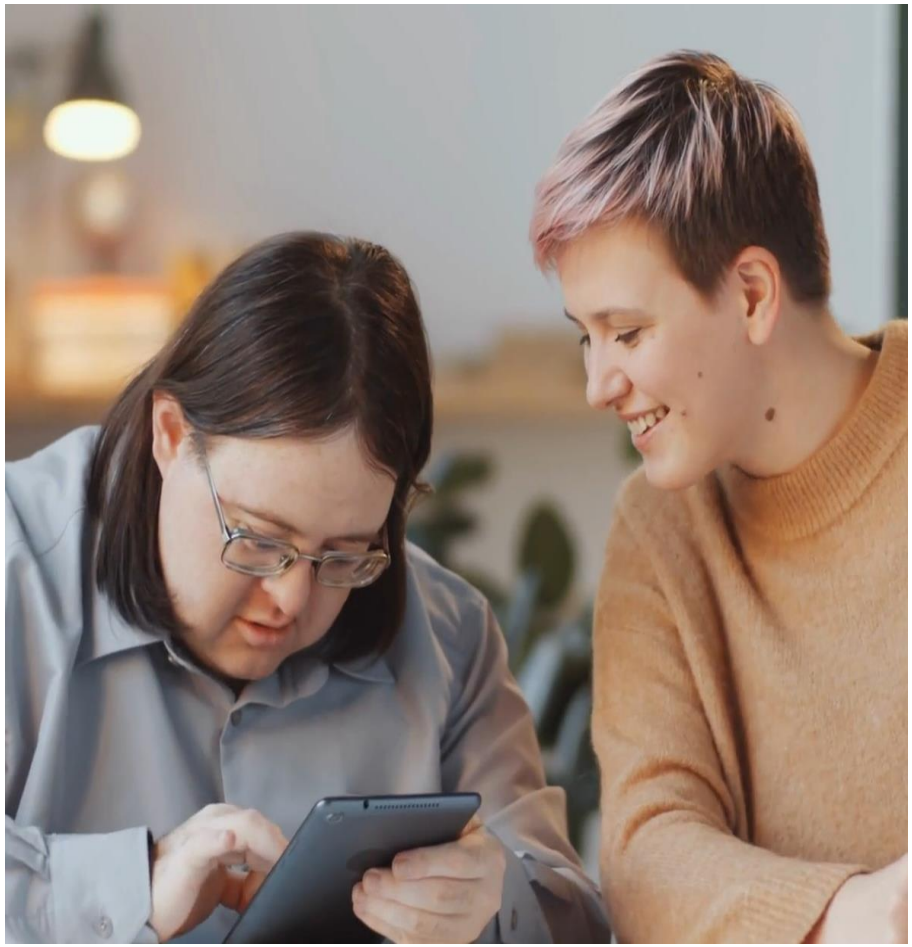
To Do List

Future planning is important for all families, and it's an ongoing process.

1. Consider wishes for the future –include the person being supported.
2. Organize information about your loved one.
3. Consider immediate and long-term housing options.
4. Evaluate and arrange financing for the future.
5. Supporting major and daily life decisions - identify and execute decision-making supports documents.
6. Prepare for employment and daily activities.
7. Making and maintaining social connections.
8. Maintain records for healthcare and medical.
9. Set up immediate and long-term professional services and supports.
10. Seek professional and legal services to execute plan.

Future Planning: The Caregiver

- Decision-Making Support (conservator, durable power of attorney, rep payee, will, healthcare directive, will, etc.)
- Activities of Daily Living (ADLs)
- Financial/asset management
- Medical Care
- Health insurance (MCD/MCR)
- Housing (current and long term)
- Transportation
- Long-term supports
  - Support services (SSI, home health/nursing home/palliative care , etc.)
  - Community engagement and social life
- Caretaker for elderly/disabled caretaker
- Replacement caretaker for the person with a disability
- End-of-Life (funeral arrangements/life insurance)



Future Planning: Person with a Disability

- Decision-Making Support/s (conservator, durable power of attorney, rep payee, Special Needs Trusts., Able Savings Acct., etc.)
- Activities of Daily Living (ADLs)
- Housing (short and long term)
- Medical Care
- Healthcare (MCD/other insurance)
- Education
- Employment
- Community engagement and social life
- Managing long-term support services (ECF Choices, SSI, Medicaid, etc.)
- Primary caretaker
- End-of-Life (Healthcare directive, will, funeral arrangements etc.)

Questions to Consider

- Is the person able to make his or her own decisions independently?
  - If not, how much support does the person need to make decisions?
  - Who can provide that support to make decisions?
  - Are formal decision-making supports needed, such as: a conservatorship, durable power or attorney, representative payee, special needs trust, etc.

- Consider where and with whom the person with a disability currently lives.
  - Where does she or he want to live in the future?
  - What supports will she or he need to live in that setting?

The Arc Center for Future Planning https://futureplanning.thearc.org/pages/learn/future-planning-101

More Questions…

- What public services or benefits does the person receive or need?
- Will current assets and future financial gifts, such as an inheritance, jeopardize the person's public benefits?
- Who are the person's extended family members and friends? (We call these natural supports.)
  - What kind of role are they willing to play in a Circle of Support?
- What are the person with a disability's interests and goals?
- How can the person maintain and build new connections in the community?

The Arc Center for Future Planning https://futureplanning.thearc.org/pages/learn/future-planning-101

Where to Start

- Determine to make a plan
- Research resources: Learn about Future Planning for individuals with disabilities, Life Care Planning, and/or Elder Care Planning.
- Seek professional help: Life Care or Elder Law attorney, Elder Care Coordinator or other professional.
- Access tools and resources to help identify needs, types of supports and best practices for future planning
- Create a care plan notebook/e-file to store the important information, legal documents, interests and wishes of the individual and/or caretaker
- Develop a Circle of Support for the person with a disability
- Reach out to friends, family and other professional supports to be included in developing the plan, as needed.

Notebook/E-file

1. Complete a Letter of Intent or Future Planning document (such as: Arc Center for Future Planning or other estate planning forms).
2. Gather important information
3. Develop a plan for the person and the aging caregiver, (if needed).
4. Store legal documents (conservatorship, power of attorney, special needs trust, will, life insurance policies, etc.) in safe and accessible location.
5. Make topic categories in the notebook/e-file to store related information and documents for each category, such as:
    - Support needs, benefits, medical provider info, healthcare info, housing, employment, income and asset info., life insurance, important people and contact info, person's likes and dislikes, daily activities, person's life and end of life wishes, etc.
6. Store the notebook in an easily accessible safe place or in computer file.
7. Inform persons of interest where to find the notebook/e-file.
8. Update the notebook annually or as needed.

Decision-Making Supports for Future Planning

Other Decision-Making Tools

Durable Power of Attorney

Power of Attorney for Healthcare

Healthcare Surrogate

Contract for Professional Services

Other Decision-Making Tools

Representative or substitute payee

Case/care management

Trusts

Living wills

Other Decision-Making Tools

Community advocacy systems

Joint checking accounts

Community agencies/services

Supported decision-making networks

System Solutions to Prevent Crisis

Future Planning in Service Systems

- Provide education and guides to families regarding Future Planning.
- Include Future Planning as part of annual planning meetings (ISP/PSCP).
- Provide staff or service providers to help families complete Future Planning documents. (Letter of Intent/Center for Future Planning)
- Refer to outside sources for Future Planning
  - Attorneys who specialize in Elder Care/ Special Needs Law
  - Center for Decision-Making Support
  - Lifelong Advocate Project

System Changes to Prevent Crisis

- Statewide Training on Future Planning and Decision-Making Supports
- Statewide Conservatorship Registry
- Statewide Office of Conservatorship Management
- Statewide Coalition (WINGS) of Aging and Disability agencies/organizations to work on addressing service gaps, system change and best practices across systems.
- Funding to help low-income families with Future Planning and legal services.

Statewide Conservatorship Registry

1. Who:

   Tennessee General Assembly (by statute) or the Supreme Court through the Administrative Offices of the Courts could mandate the use of a statewide registry of conservators.

2. Why:

   A statewide registry or database could provide a solution for the lack of conservatorship oversight here in Tennessee by creating a relatively inexpensive and easy way to track conservatorships, especially in larger counties like Shelby, Hamilton, and Knox.

Statewide Coalition (WINGS)

Working Interdisciplinary Network of Guardianship Stakeholders

WINGS is a multi-disciplinary problem-solving body that relies on court-community partnerships to:

1. Oversee conservatorship practices
2. Address key policy issues
3. Improve the current system of guardianship and less restrictive alternatives
4. Engage in outreach and education
5. Enhance the quality of care and quality of life of vulnerable adults

https://www.americanbar.org/content/dam/aba/administrative/law_aging/final-wings-brochure.pdf

Statewide Office of Conservatorship Management

1. Maintain a database
2. To keep case notes for each case regarding welfare and court hearings
3. Document who serves as conservator, and
4. Keep track of assets being managed by the conservator
5. Track of a conservator has been removed for maleficence.
6. Notify the court when concerns arise

The Metropolitan Government of Nashville and Davidson County, Tennessee
Office of Conservatorship Management

Office of Conservatorship Management

In 2014, an independent group of professionals reviewed the Guardianship and Conservatorship processes and procedures in Davidson County and found different areas that could be improved upon. After reviewing over 2,000 cases, the Task Force acknowledged various recommendations for the Conservatorship process. They found additional support was needed for the State Trial Courts in order to provide assistance to the judges in their role as Super Fiduciary.

These recommendations paired with the approval of the of former Metropolitan Mayor Karl Dean, the Metropolitan Council and the Metropolitan Government of Nashville and Davidson County, Tennessee led to the creation of the Office of Conservatorship Management, or “OCM”.

Though independent from the State Trial Court Judges, the OCM supports the courts in their conservatorship oversight function. The independent and neutral nature of the OCM case review function is similar to the support provided to the court by a Guardian Ad Litem.

OCM Functions

Welfare Review

Financial Review

Education

Resources

How have we helped?

Even when issues are identified, the OCM endeavors to help conservators be empowered to be successful fiduciaries - by discussing findings, providing constructive recommendations for case improvement, and connecting fiduciaries with needed resources.

Fiduciary missteps identified by the Office of Conservatorship Management:

Uncovered over half of a million dollars in funds misappropriated by fiduciaries.

Located undisclosed real property.

Identified real property purchased and sold without court approval.

Identified cases in which conservators used the respondent's resources for their own benefit, rather than for the benefit of the respondent.

2 Trustees were removed due to breach of duties identified by the OCM.

19 conservatorships were expanded/changed due to issues identified by the OCM.

70 conservators were removed/replaced due to issues as identified by the OCM.

42 conservatorships were terminated due to action taken by the OCM

Inventory, Accountings, Bond and Property Management Plans were ordered due to issues identified by the OCM.

OCM Case Scenarios

The first involves an adult only child who was appointed guardian of the person and property for her father. In addition to the responsibilities of serving as guardian for her father, she had four children. The guardian was apprised of her fiduciary responsibilities however no specific training was required. Unfortunately, the guardian failed to file annual accountings and inappropriately managed the respondents bank accounts. These actions resulted in a $30,000 judgment against the guardian. While she remained guardian of her father's person, she was removed as guardian over property. She later stated had she fully understood the responsibilities, she may not have agreed to be the guardian over the property of her father.

OCM Case Scenarios

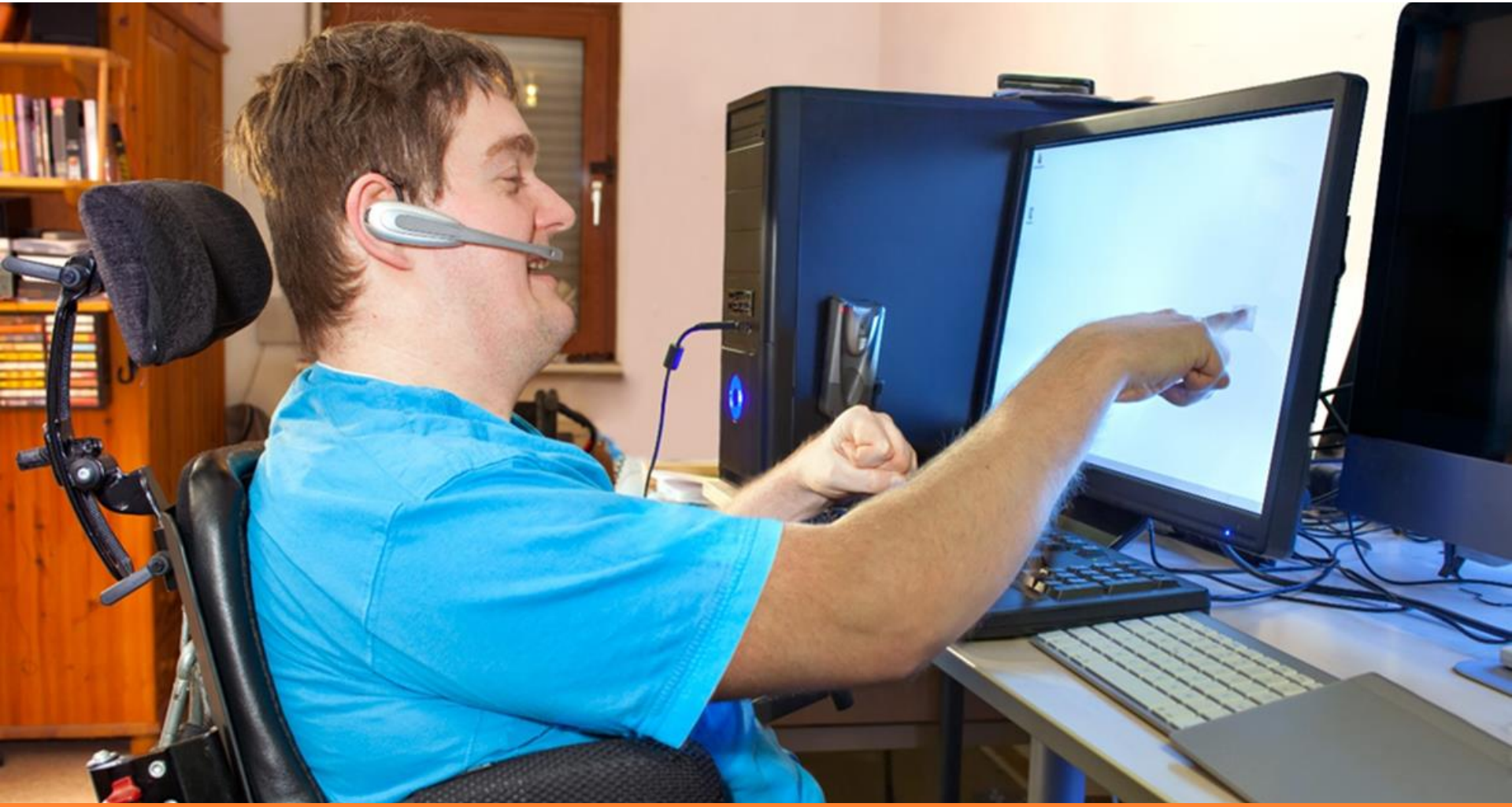
The second involves an aunt who was appointed guardian of the person and property of her niece. The clerk received a call from a local real estate agent after the guardian entered a contract to purchase a house for the respondent with the respondent's funds. After an investigation, it was discovered the guardian withdrew excessive cash from the respondent's bank accounts for trips and lavish purchases for the respondent. Moreover, the guardian purchased a $36,000 truck for the respondent's benefit without court approval. The guardian contended that she was only attempting to make her niece happy and was unaware she needed court permission to make the large cash withdrawals, take vacations or make home and vehicle purchases. The review hearing resulted in a judgment against the guardian in the amount of $48,000.

OCM Case Scenarios

The third involves a son who was appointed guardian over his mother. The court found through its welfare review process that the respondent was running out of money and would soon no longer be able to afford to live at her current residence. A review hearing was held to discuss the lack of accounting and diminishing funds. The hearing uncovered that the guardian was withdrawing money from the joint bank account held by the respondent and son to pay for vacations, food, utilities, and clothing among other various items. The court provided several chances for the guardian to provide accounting and receipts. However, the guardian failed to provide the annual accountings. The court found that while some expenses were for the benefit for the respondent, the majority were not. Unfortunately, the respondent's home was sold to pay for her care in a nursing facility. The court rendered a judgment against the guardian in the amount of $65,000.

OCM Case Scenarios

The fourth involves an elderly woman that was a hoarder with questionable hygiene. She suffered a stroke was admitted to the hospital. She did not have anyone designated to make medical decisions for her. Therefore, the hospital filed for the court to appoint an Expedited Limited HealthCare Fiduciary to make the initial decisions. A local attorney was appointed as her ELHF. During that process, it was discovered that in her home she had dozens of dead cats in Tupperware containers and her home was a health hazard for anyone to enter. She was placed in an assisted living facility. She did not have any friends or family to retrieve her belongings from inside the house. Her house was sold and demolished. The proceeds are being used for her care. She now has a conservator to help make decisions for her.



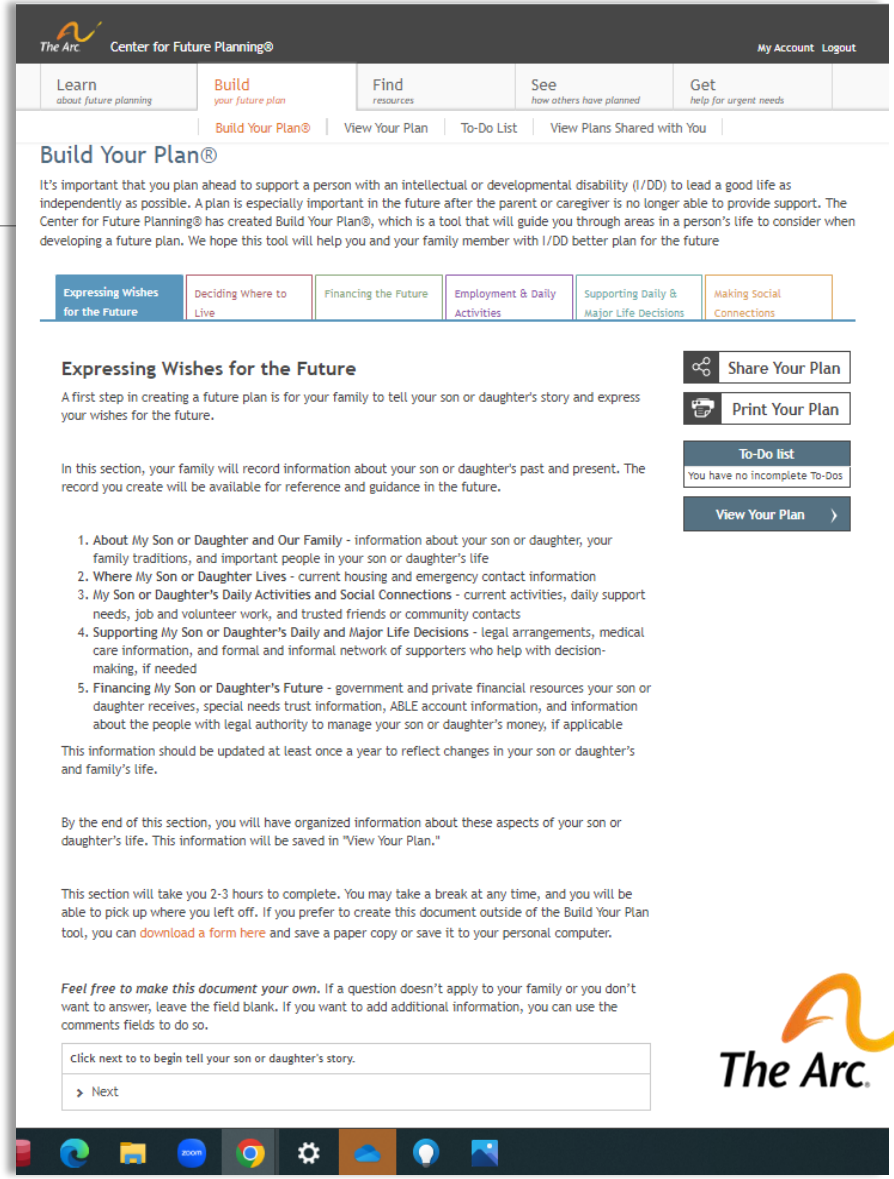
Tools and Resources

The Arc: Center for Future Planning

Website that enables the person with a disability, family or professional to develop a Future Plan with/for the person with a disability.

- Contains several support categories and asks question within each category
- Develops a life plan and stores within the user's account
- Can be printed and modified as needed.

https://futureplanning.thearc.org/

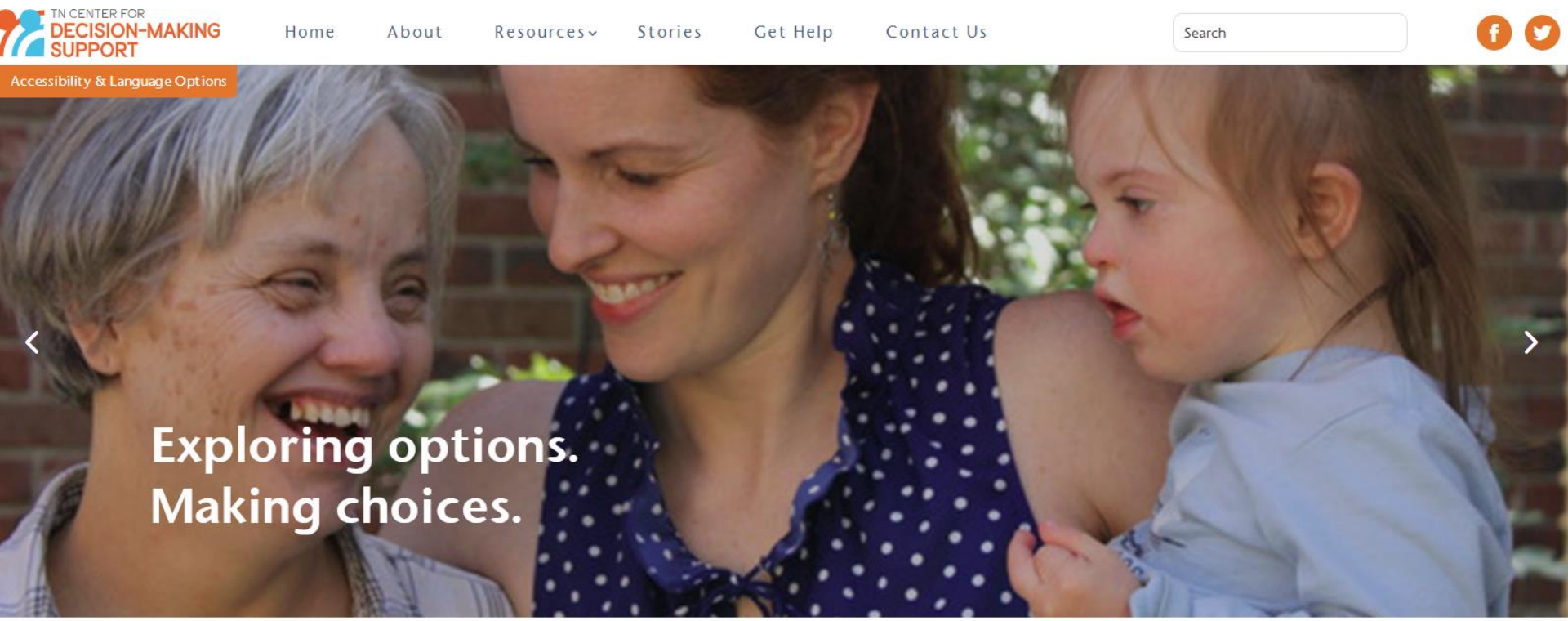


Lifelong Advocate Program

Arc of Davidson County's new program- Launch 1/1/2024

- Provides lifelong advocacy for individuals with IDD and no caretaker
- Sets up a Future Plan with current caretaker.
- Enacted when current caretaker is deceased or incapacitated
- Allows Arc Advocate to oversee care of the individual as caretaker has defined in the plan
- Paid services
- Fee based on frequency of check in (monthly, semi-monthly, quarterly, semi-annually or annually)
- Must have trust set up to pay for services
- Advocates cannot serve as Rep Payee, DPOA, Conservator, or Trustee to the individual.
- Website launch Jan 2024

TN Center for Decision-Making Support



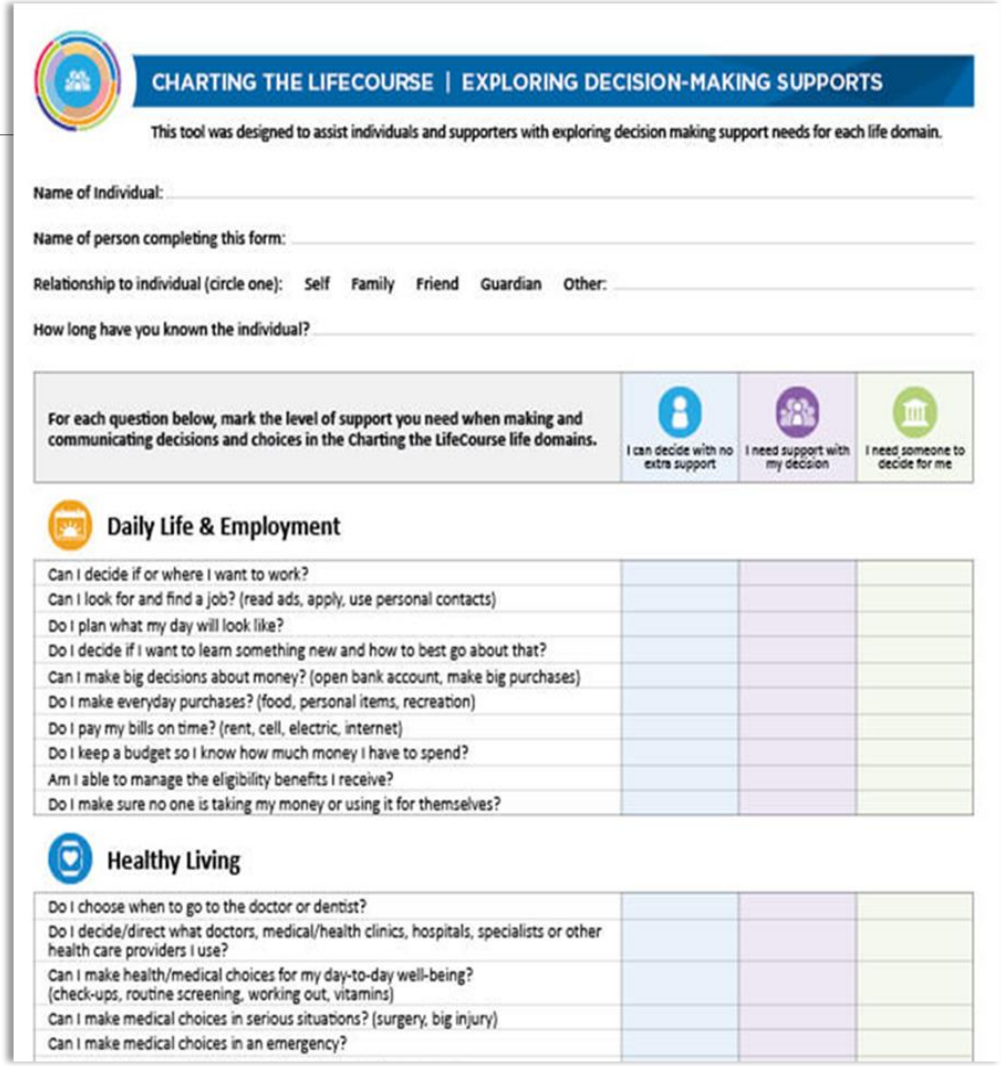
https://www.tndecisionmaking.org/

Charting the LifeCourse

Exploring Decision-Making Supports Tool

https://www.lifecoursetools.com/lifecourse-library/exploring-the-life-domains/supported-decision-making/

This tool was developed by the Charting the LifeCourse Nexus (©2020 Curators of the University of Missouri, UMKC IHD, UCEDD)



CHARTING THE LIFECOURSE | EXPLORING DECISION-MAKING SUPPORTS

This tool was designed to assist individuals and supporters with exploring decision making support needs for each life domain.

Name of Individual: _____

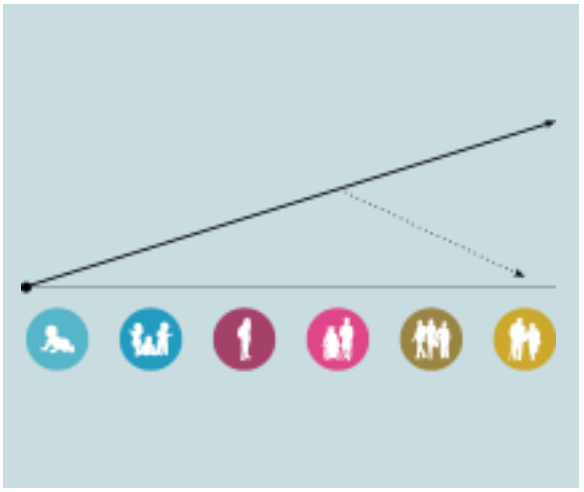
Name of person completing this form: _____

Relationship to individual (circle one): Self Family Friend Guardian Other: _____

How long have you known the individual? _____

For each question below, mark the level of support you need when making and communicating decisions and choices in the Charting the LifeCourse life domains.	I can decide with no extra support	I need support with my decision	I need someone to decide for me
Daily Life & Employment			
Can I decide if or where I want to work?			
Can I look for and find a job? (read ads, apply, use personal contacts)			
Do I plan what my day will look like?			
Do I decide if I want to learn something new and how to best go about that?			
Can I make big decisions about money? (open bank account, make big purchases)			
Do I make everyday purchases? (food, personal items, recreation)			
Do I pay my bills on time? (rent, cell, electric, internet)			
Do I keep a budget so I know how much money I have to spend?			
Am I able to manage the eligibility benefits I receive?			
Do I make sure no one is taking my money or using it for themselves?			
Healthy Living			
Do I choose when to go to the doctor or dentist?			
Do I decide/direct what doctors, medical/health clinics, hospitals, specialists or other health care providers I use?			
Can I make health/medical choices for my day-to-day well-being? (check-ups, routine screening, working out, vitamins)			
Can I make medical choices in serious situations? (surgery, big injury)			
Can I make medical choices in an emergency?			

Charting the LifeCourse Nexus



https://www.lifecoursetools.com/

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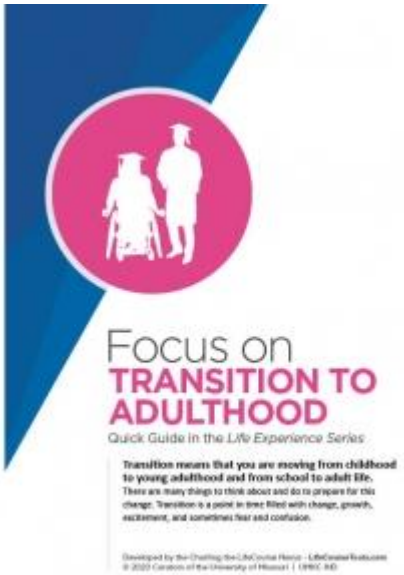
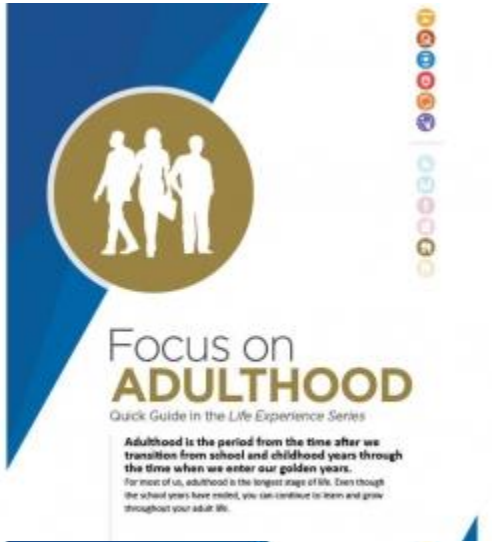
Charting the LifeCourse

Life Stages Guides

Life Stages Guides help individuals, family members and professionals think about the questions to ask, options to consider and things to discuss as they work to develop a vision of a good life for the person with a disability.





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https://www.lifecoursetools.com/lifecourse-library/exploring-the-life-stages/

References and Resource Links

- The Arc Center for Future Planning, https://futureplanning.thearc.org/
- A Life Care Plan: Helping You Navigate THE AGING JOURNEY: Adler, McGinnis, Takacs, Graham, Magee, King, RothKoff, 2022
- TN Center for Decision-Making Support, https://www.tndecisionmaking.org/
- TCAD, Tennessee State Plan on Aging 10/1/2017-9/30/2021, https://www.tn.gov/content/dam/tn/aging/documents/TN_State_Plan_on_Aging_2017-2021.pdf
- TCAD, Tennessee State Plan on Aging 10/1/2021-9/30/2025, https://www.tn.gov/content/dam/tn/aging/images/TN%20State%20Plan%20on%20Aging%202021%20-%202025.pdf
- Charting the LifeCourse Nexus, https://www.lifecoursetools.com/

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Questions?

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Thank You!!

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Tell us what you thought and help us improve by taking a brief survey:

https://redcap.vanderbilt.edu/surveys/?s=PWYH9EH79Y

The Arc