

Planning for Transition: Decision-Making Support

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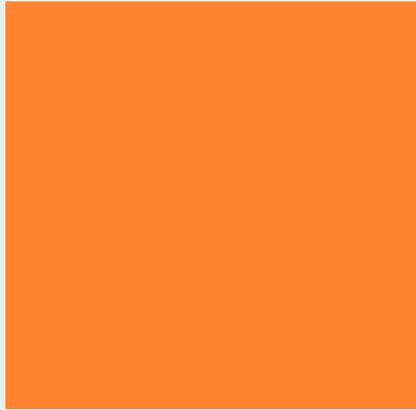
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Council on
Developmental Disabilities



TN CENTER FOR
**DECISION-MAKING
SUPPORT**



Preparing for Transition

There are many decisions to make when preparing for transition to adulthood.

- Kind of diploma to obtain.
- Type of post-secondary education and training to seek.
- Where to get the education and training.
- Does the young adult need or qualify for benefits.
- Are other disability services needed?
- Where do we begin?

These decisions can be overwhelming.



Decision-Making Support Planning

Decision-making support planning can help.

- Identify the type and amount of help the person with disability needs to make decisions.
- Identify the key people or supports needed to assist in making those decisions.
- Set up the support plan, documents and/or agreements).
- Unique to each person's needs.

Research Shows...

When individuals with disabilities practice decision-making they obtain:

- Better quality of life
- More employment and community engagement
- Better physical and psychological health
- Welfare and safety.



Sources: Powers et al., 2012; Shogren, Wehmeyer, Palmer, Rifenbark, & Little, 2014; Khemka, Hickson, and Reynolds, 2005; National Core Indicators, TN



Understanding Decision-Making Supports

What are decision-making supports (DMS)?

DMS are tools, documents, or supports that help an individual to understand and make decisions about their life.

***Informal* decision-making supports:**

- Trusted advisors
- Support Team
- Direct Support Providers
- Assisted technologies
- Processes- role playing, having someone attend Dr. appointments, etc.

***Formal* decision-making supports:**

- Conservatorships
- Durable Power of Attorney
- Special Needs Trust
- HealthCare Directives
- Supported Decision-Making Agreement
- FERPA release

Conservatorship vs: “*Alternatives*” other decision-making supports

Conservatorship:

- Court order
- Removes the legal rights
- Based on the determination of incapacity

Other decision-making supports:

- Do not remove legal rights
- Gives other people the authority to help make decisions
- Person **must have** decision-making “*capacity*” for most of these supports. (Ex: POA, DPOA, supported decision-making, etc.)

What is decision-making capacity?

The ability to understand the benefits, risks and choices; make a decision; and share (communicate) that decision.

- Ability to share (communicate) the decision may come in different forms based on the person's disability, such as: verbal, written, sign language, technology, etc.



Capacity (cont.)

- Presume capacity
- Capacity can be developed
- Capacity can be fluid
- Capacity cannot be based solely on IQ
- Capacity is not based solely on a diagnosis
- Lack of opportunity to make decisions can prevent people from developing capacity or further decrease capacity. (Salzman, 2010)
- **“Bad” decisions ≠ lack of capacity (dignity of risk)**



Types of Decision-Making Supports

Decision-Making Supports

- **Conservatorship**
- **Durable Power of Attorney**
- **Supported Decision-Making**
- **Representative Payee**
- **Special Needs Trust**
- **Able Savings Account**
- Health Care Surrogate
- Health Care Directive
- Will/End of Life Planning

Conservatorship overview

- Determination of **incapacity**. Court issues an order removing the person's decision-making rights.
- Should be **limited to only** those areas that the person does **not have capacity** to make decision.
- Can and should preserve as many decision-making rights as possible.
- The conservator has the duty to make decisions based on the best interest of the individual.
- Court becomes responsible for the person with a disability.
- Conservators are representatives (agents) of the court.

Overview (cont.)

- Conservators should consider what's important to the person and give them a voice in the decision-making process.
- Once a person's rights are removed it is difficult to get those rights restored.
- Conservatorship should not be filed simply because an individual with a disability has turned 18 or for convenience.
- Individuals are “**presumed**” to **have capacity** until their decision-making rights are removed by the court.
- Conservatorship should be the last resort.

Durable Power of Attorney (DPOA)

Legal document used to give someone else the authority to make decisions on the person's behalf.

- Person ***must have capacity*** to authorize the DPOA to make decisions on the individual's behalf.
- Can be cancelled at any time as long as the individual has decision-making capacity.
- The ***DPOA continues even if the individual no longer*** has decision-making capacity.
- Can be used for **finances, healthcare, medical, or other life decisions.**
- Legal assistance is recommended when setting up a DPOA but is not required.
- The individual does ***not*** lose their decision-making rights.
- The document requires the signature of 2 witnesses and/or a signature of a notary.

Representative Payee

A Representative Payee can be assigned by the Social Security Administration (SSA) to help an individual with disabilities to manage their SSI/SSDI benefits.

- The individual with a disability does not lose his/her decision-making rights.
- Rep. Payee is designated to help the individual manage their benefits.
- Rep. Payee must use the money for the individual's needs and wants only.
- Rep. Payee must maintain records of the financial dealings regarding the individual's finances.
- Rep. Payee is accountable to SSA to submit annual reports of the individual's finances and expenditures.

Special Needs Trust

A legal plan executed by an attorney for placing funds and other assets in the control of someone the person with a disability trusts, called a “trustee”. The trustee can be a family member, an attorney/accountant or organization who is authorized to manage the trust.

- Protects money and property without requiring the court to find the person incapacitated.
- Enables the individual to remain eligible for benefits.
- Funds/assets are used to meet needs not covered by governmental benefits.(ie.: classes, hobbies, furniture, computer equipment, etc.)
- It is recommended to seek an attorney who specializes in Special Needs Law to help set up your trust.
- There are different types of Special Need Trusts.

ABLE account

- Federal savings program that enables individuals with disabilities to save money beyond the normal assistance program resource limits.
- Can be used for: education, housing, transportation, personal support services, assisted technology, and more.
- Allows individuals with disabilities to save up to \$100,000 without affecting their government benefits. May place up to \$16,000/yr. in the acct.

To be eligible individuals must:

- Have a been diagnosed with a qualifying disability before they turned 26 years of age, and
- Be eligible to receive SSI, SSDI or have been diagnosed from a physician with an intellectual, physical or mental disability that causes severe limitation that is expected to last more than 12 months.

FERPA waiver (release)

FERPA Family Educational Rights and Privacy Act is a federal law that protects the privacy of student education records maintained by or on behalf of educational agencies or institutions (20 USC Sec. 1232g; 34 CFR part 99).

- FERPA affords parents certain rights with respect to their children's educational records (to amend the docs, release the docs which include IEP docs).
- These rights transfer to the student when he or she turns 18 or attends a post secondary school at any age. The student then becomes an "eligible student under FERPA."
- A waiver signed by the student will allow parents to continue accessing the student's school records.
- Can give parents authority to attend IEP meetings depending on how the form is written.



Supported Decision-Making

What is Supported Decision-Making in TN?

Supported decision-making* refers to the *idea* that a person has the right to make decisions to the full extent of their **capacity**, even as they get needed support.



- It is a concept that can be practiced throughout life.

*Center for Decision-Making Support website definition

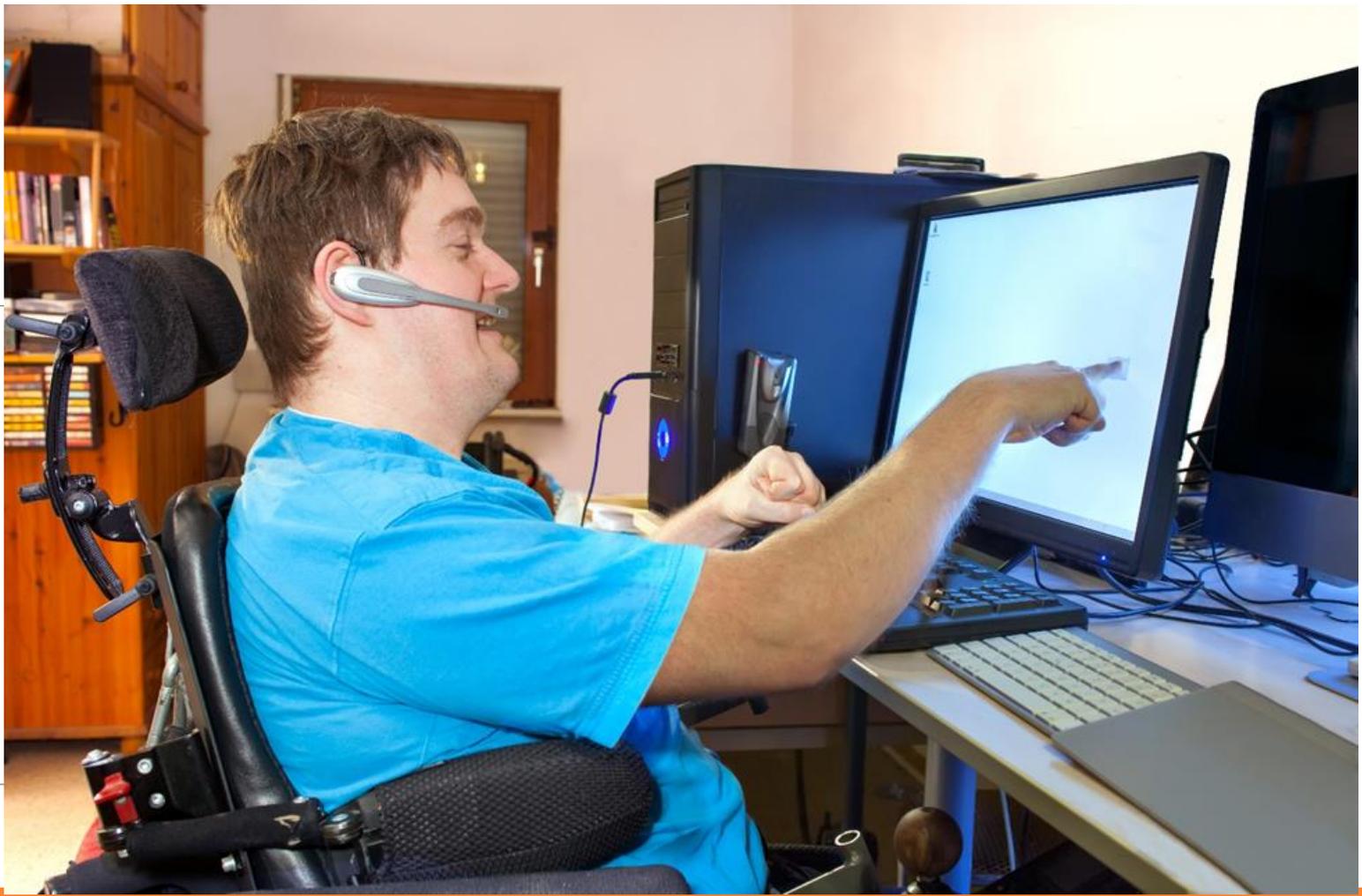
What is Supported Decision-Making ? (cont.)

Process of using a **person or team of trusted advisors** to help the person with a disability to make decisions by helping them understand the options, benefits, risks and consequences of a decision.

- Supported Decision-Making allows a person to make as many decisions as possible.
- Tennessee ***does not*** have a Supported Decision-Making law but that does not prevent someone from using Supported Decision-Making.

What is Supported Decision-Making ? (cont.)

- Supported Decision-Making Agreement can be used as a tool but ***may not be used as legally binding document*** (such as Durable Power of Attorney).
- Can be ***practiced*** with other decision-making supports (such as a Durable Power of Attorney).
- Can be used as the primary decision-making support if the person has decision-making capacity.



Resources and Tools

TN Center for Decision-Making Support

- Virtual resource center that provides information, resources, and referral services related to decision-making support options.
- Provides limited one-on-one assistance for individuals who need a higher level of assistance navigating information.
- Referral assistance to legal counsel with a partnership with Disability Rights Tennessee.
- Provides education and best practices for supported decision-making and decision-making support future planning.





Exploring options.
Making choices.

Learn More

Making decisions for your future

The tools on this website can help you decide how much support you need when making choices about your own life. These choices could be about where to live, where to work, how to spend your time during the day, or how to spend your money.

Tndecisionmaking.org

TN Center for Decision-Making Support

Learning to make decisions one choice at a time.

The Arc Tennessee

Making a Choice Tool

 **MAKING A CHOICE** 

_____ HELPS ME DECIDE. I TRUST, UNDERSTAND, RESPECT AND LISTEN TO THEM

ABOUT		 LIKE ABOUT IT 	 DON'T LIKE ABOUT IT 
CHOICES			
1			
2			
3			
MY DECISION			

10/6/2018

Charting the LifeCourse Nexus

Exploring Decision-Making Supports Tool



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?			

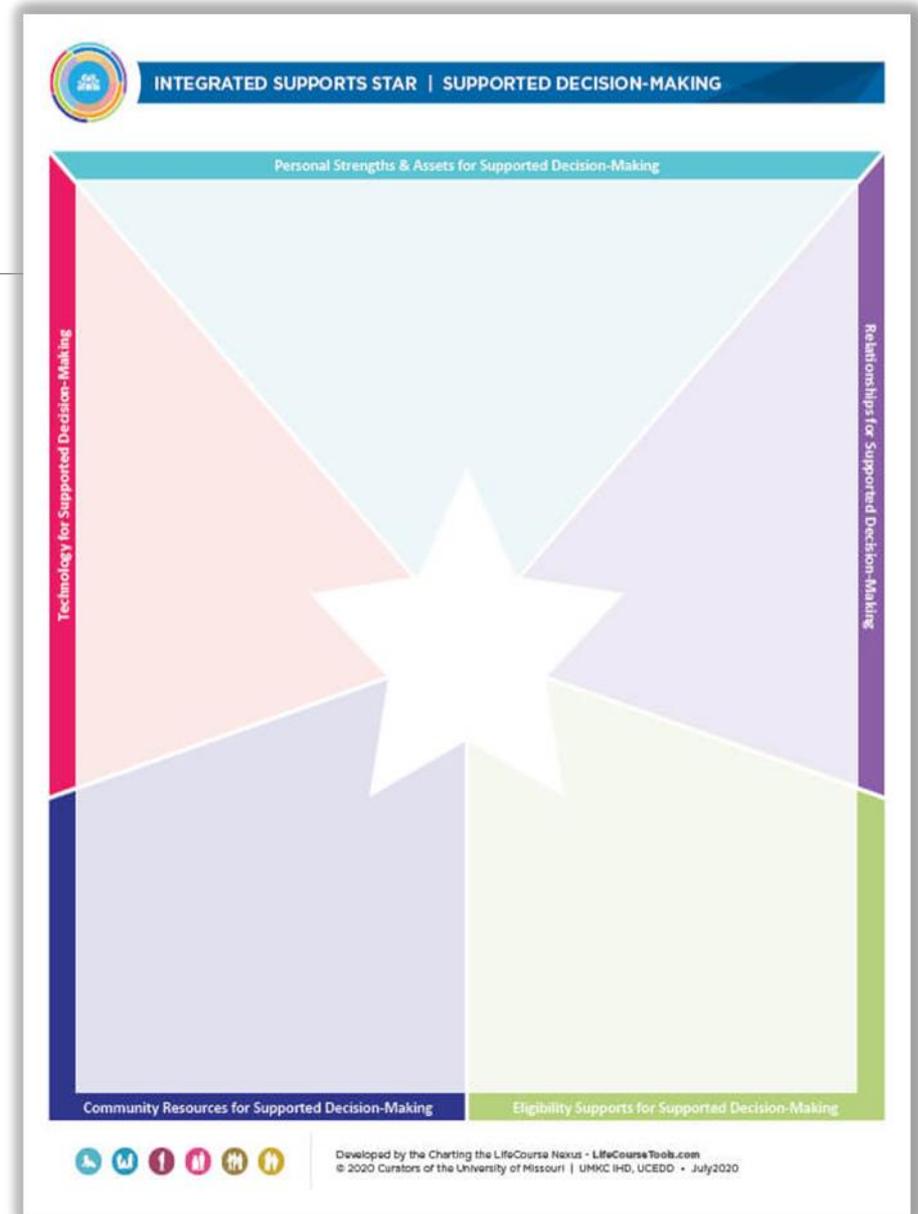
These tools were developed by the Charting the LifeCourse Nexus (©2020 Curators of the University of Missouri, UMKC IHD, UCEDD)

Charting the LifeCourse:

Integrated Supports Star- Supported Decision-Making

[Supported Decision-Making – LifeCourse Nexus \(lifecoursetools.com\)](https://lifecoursetools.com)

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



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Sample Decision- Making Plan

Sample Decision-Making Plan

My name is: _____

Today's date is: _____

My address is: _____

My phone number is: _____

My email address is: _____

I want people to help me make decisions. The people who will help me are called supporters. I can say what kind of help my supporters will give me. My supporters will give me the support I need and want to make my own decisions. This means my supporters will help me understand the situations I face and the decisions I have to make. This document does not give my supporters permission to make decisions for me. I can stop this agreement at any time. My supporters can stop their agreement at any time.

Supporters

My supporter(s) are:

Supporter #1

Name: _____

Address: _____

Phone number: _____

Email address: _____

I want this person to help me with (check all that apply):

- Making choices about food, clothing, and where I live
- Making choices about my health
- Making choices about how I spend my time
- Making choices about where I work and where I go to school



Questions ?



The Arc Tennessee

Contact the Team:

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Call: (615) 248-5878, Ext. 322

Toll Free: (800) 835-7077

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Disability Rights Tennessee

Contact the Team:

Intake Department

Call: (800) 342-1660

Email: gethelp@disabilityrightstn.org

Fill out form: <https://www.disabilityrightstn.org/get-help>

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Council on Developmental Disabilities

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Resources

- The Arc Tennessee's Alternatives to Conservatorship and Conservatorship Handbook: https://www.tndecisionmaking.org/wp-content/uploads/Conservatorship_Handbook.pdf
- The Arc US, Center for Future Planning; <https://futureplanning.thearc.org/>
- American Bar Association's PRACTICAL Guide – Starts with Presume Competence: http://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool.html
- Office of Conservatorship Management; <https://officeofconservatorshipmanagement.nashville.gov/>
- ASAN's Self Advocacy Tool Kit <http://autisticadvocacy.org/policy/toolkits/choices/>
- ACLU's Resource Library: <https://www.aclu.org/other/supported-decision-making-resource-library>
- SDM National Resource Center: <http://www.supporteddecisionmaking.org/>
- VistaPoints *The Special Needs Trusts & Resource Center*: <https://vistapoints.org/>
- Charting the LifeCourse Nexus, Supported Decision-Making Tools, website <http://www.lifecoursetools.com/lifecourse-library/exploring-the-life-domains/supported-decision-making>

Thank You!!

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

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



Contact me directly:
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