

Supporting Self-Determination and Employment through Supported Decision-Making



 **HCBS
CONFERENCE**
Home & Community-Based Services

**2020 Virtual Home
and Community-Based
Services Conference**

www.HCBSConference.org

**ADvancing States Fall
Meeting: December 1**

**HCBS Conference:
December 2-3 & 8-10**

Our Speakers



- **Erin Leveton:** Director, *Alvarez and Marsal*
- **Jane St. John:** Charting the LifeCourse Nexus team at University of Missouri, Kansas City – Institute for Human Development, UCEDD
- **Jill Shoemate:** Director of State Support Coordination and Community Living Coordinators, *Missouri Division of Developmental Disabilities*
- **Emily Ornstein:** Person Centered Thinking Project Manager, *District of Columbia Department on Disability Services*
- **Morgan K. Whitlatch:** Legal Director, *Quality Trust for Individuals with Disabilities*

The Nexus of Supporting Families and Supported Decision-Making to Improve Employment Outcomes

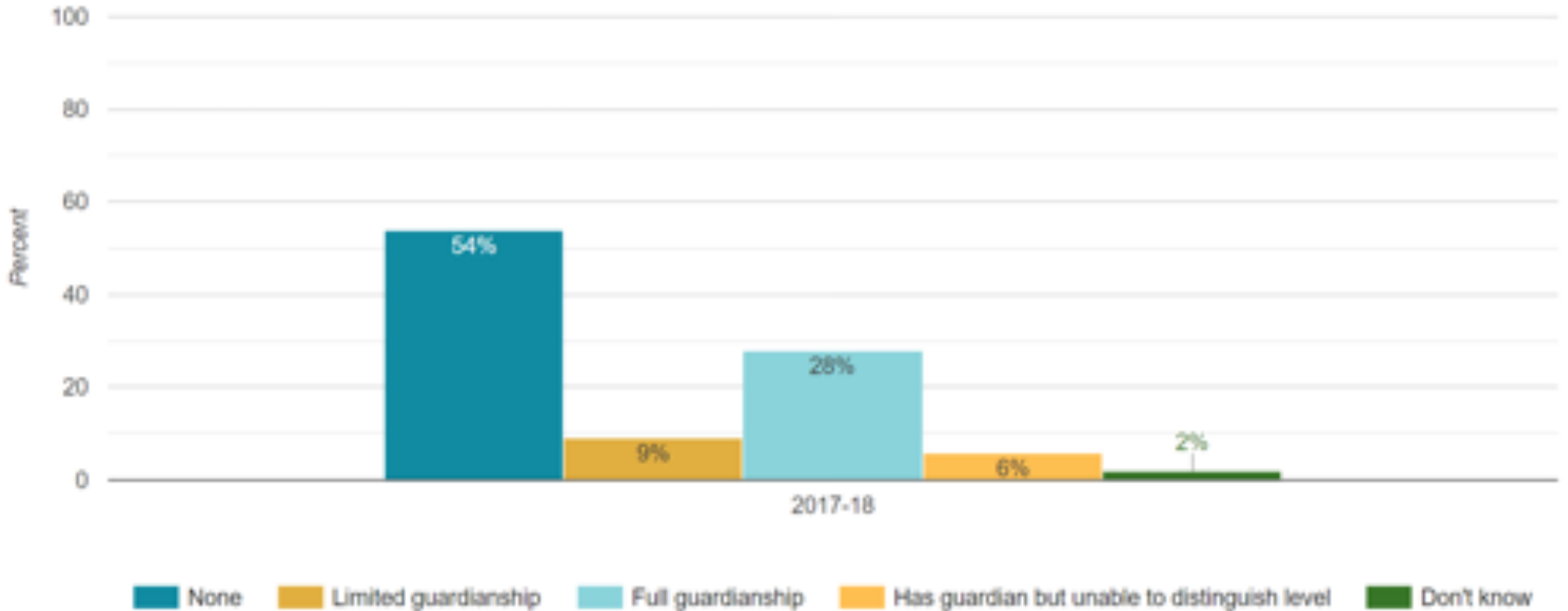


Understanding Key Terms

Guardianship is a legal process “allowing a state court to appoint decision-making powers to another person on behalf of an individual based on a determination of impaired decision-making capacity” (Dinerstein, Grewal & Martinis, 2016, p. 436).

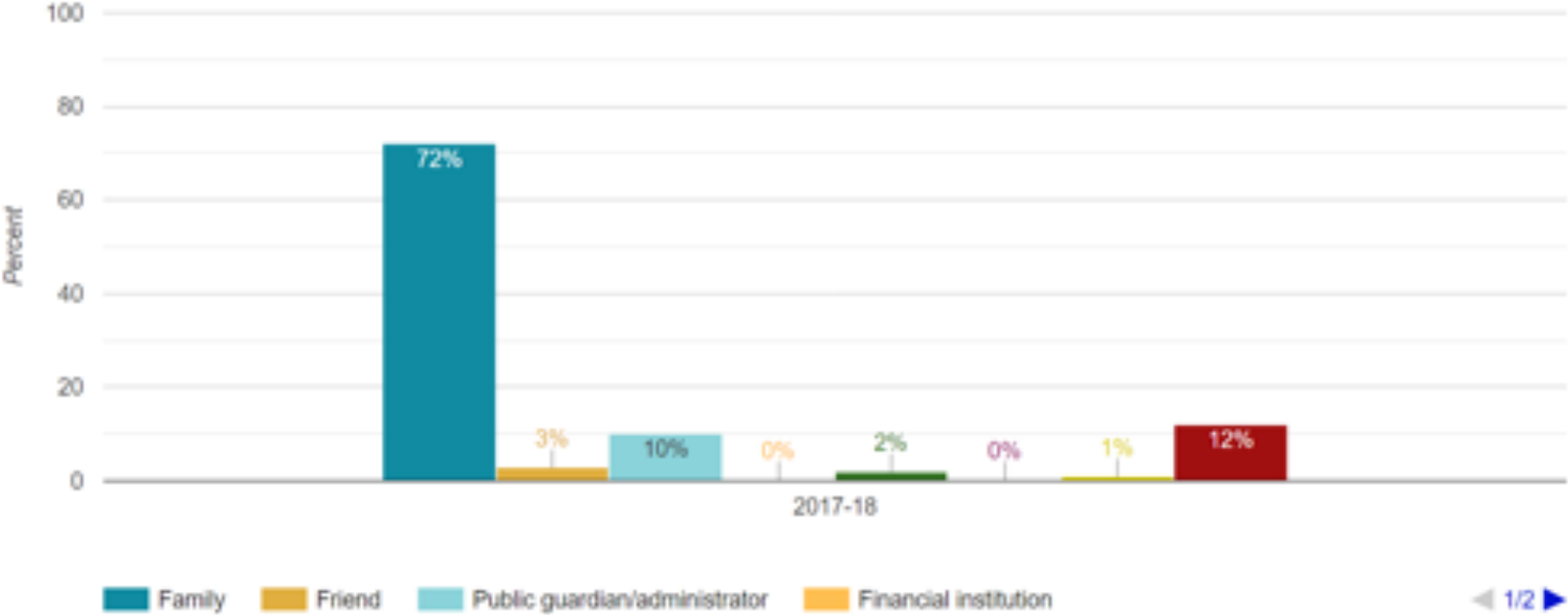
Supported decision-making is a flexible alternative to guardianship which provides a process that recognizes people with disabilities as persons before the law, providing a pathway to exercise legal capacity by focusing on developing supports to enable autonomous decision-making.

Guardianship Prevalence



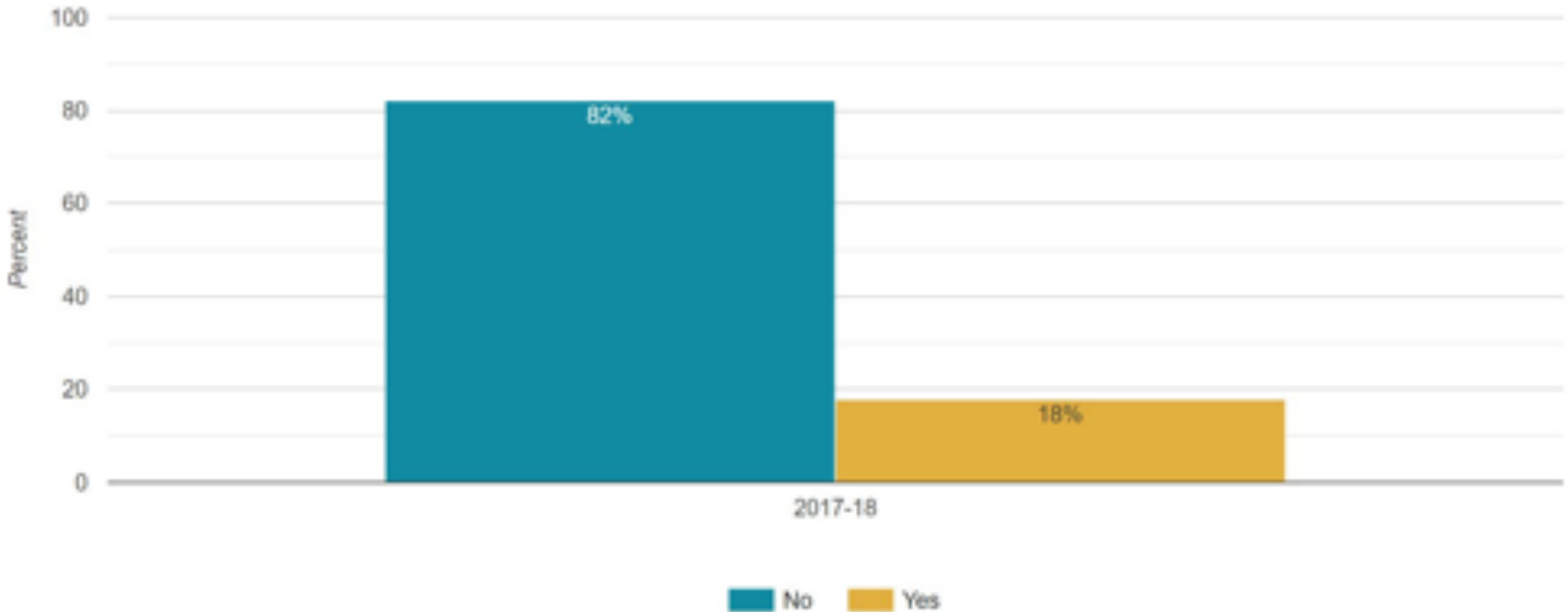
Source: National Core Indicators (2017-2018)

Guardianship Relationships



Source: National Core Indicators (2017-2018)

Person Has Paid Job in the Community



Source: National Core Indicators (2017-2018)

Connection Between Employment & Self-Determination

- People receiving public IDD services with a guardian are significantly less likely:
 - To work in a paid community job
 - To have employment as a goal in their service plan.

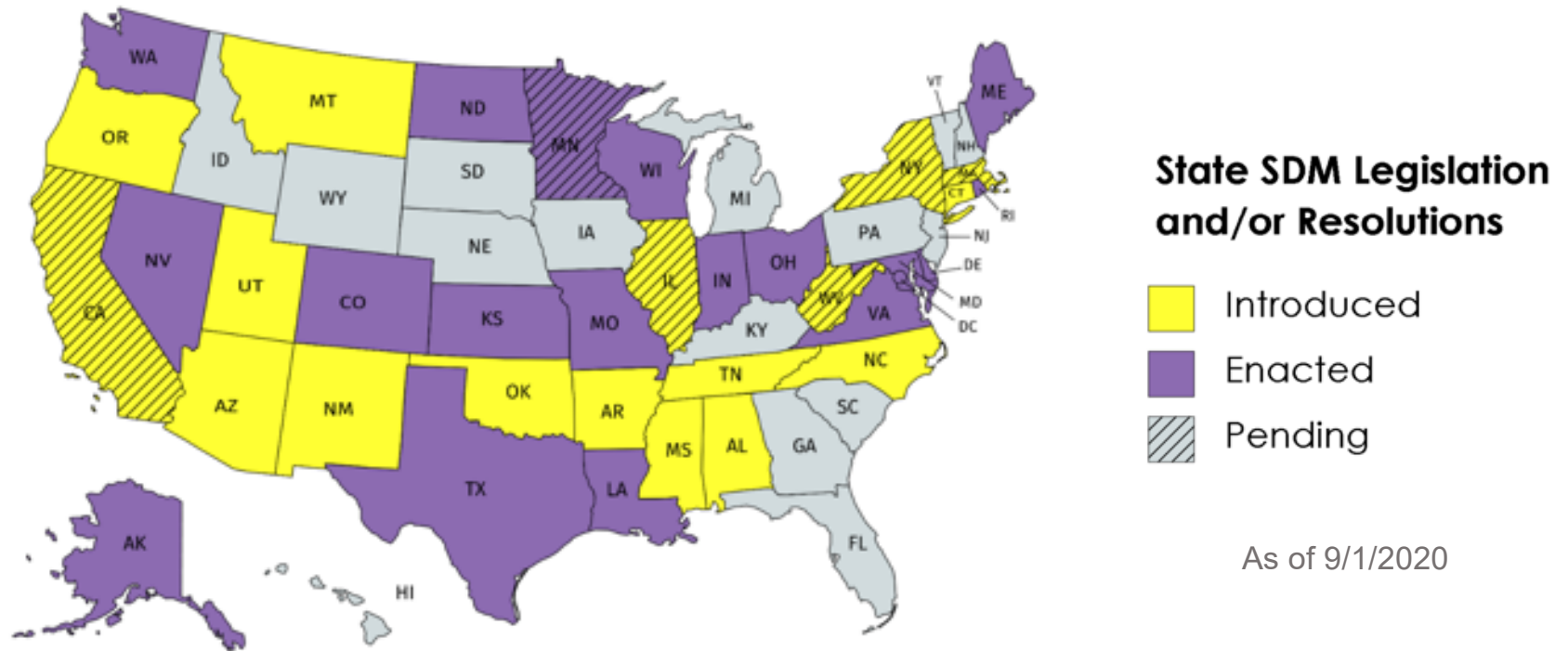
(See Bradley et al., National Core Indicator Data Brief, 2019)

Importance of Vision for A Good Life

- Parental expectations and parental involvement have been identified as an evidence-based predictor of improved post-school outcomes for students with disabilities
 - Mazzotti et al., 2015; Test et al., 2009

Supported Decision-Making: U.S. Trends

Actions by State Legislatures



Visit www.SupportedDecisionMaking.org to learn more!

Looking Nationally



- **U.S. Administration for Community Living**
- **National Resource Center for Supported Decision-Making** (2014 to present)
- **National Guardianship Association** (2016)
- **Social Security Advisory Board** (2016)
- **AAIDD & The Arc of the U.S.** (2016)
- **American Bar Association** (2016 & 2017)
- **Uniform Law Commission** (2017)
- **National Council on Disability** (2018 & 2019)
- **U.S. Senate Special Committee on Aging** (2018)

District of Columbia: Building a Culture of Support

Building a Culture of Support



- Person-Centered Thinking
- DC Supporting Families Community of Practice (SF CoP) and Family Support Council (FSC)
- Employment First: EFSLMP, Partners in Employment
- No Wrong Door LTSS Implementation Grant
- National CoP on Cultural & Linguistic Competency
- HCBS Transition Plan
- NRCSDM Technical Assistance

Building a Culture of Support

“In a culture of coordinated supports model, people with disabilities, and the governmental agencies and organizations providing services to them, use Supported Decision-Making to identify each person’s goals, preferences, and needs and then coordinate their efforts to develop and implement person-centered plans that provide supports designed to meet and achieve them.”

-Blanck, Martinis, Shogren, Wehmeyer

Building a Culture of Support

Employment and Discovery Toolkit

FSC Report on Perspectives of Families & People Supported

DC SF COP SDM Trajectory

SDM Training for HHS Cluster and Train-the-Trainer Module

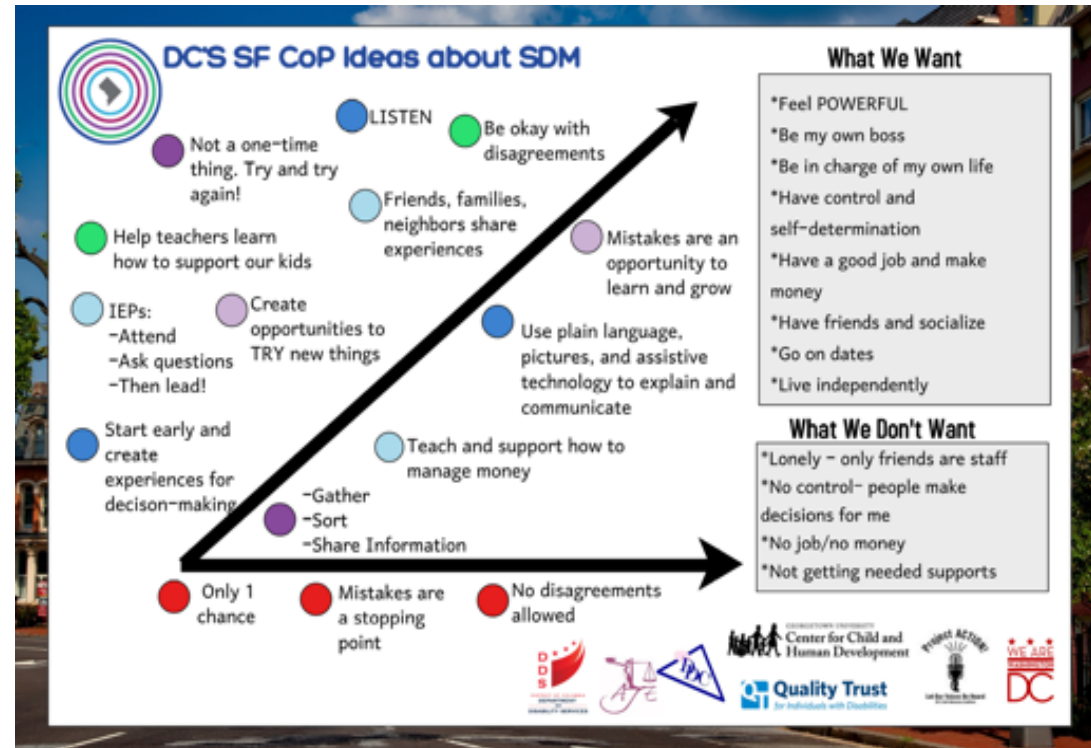
29 Formal Letters Distributed and Resources Online

Name: _____ Date: _____

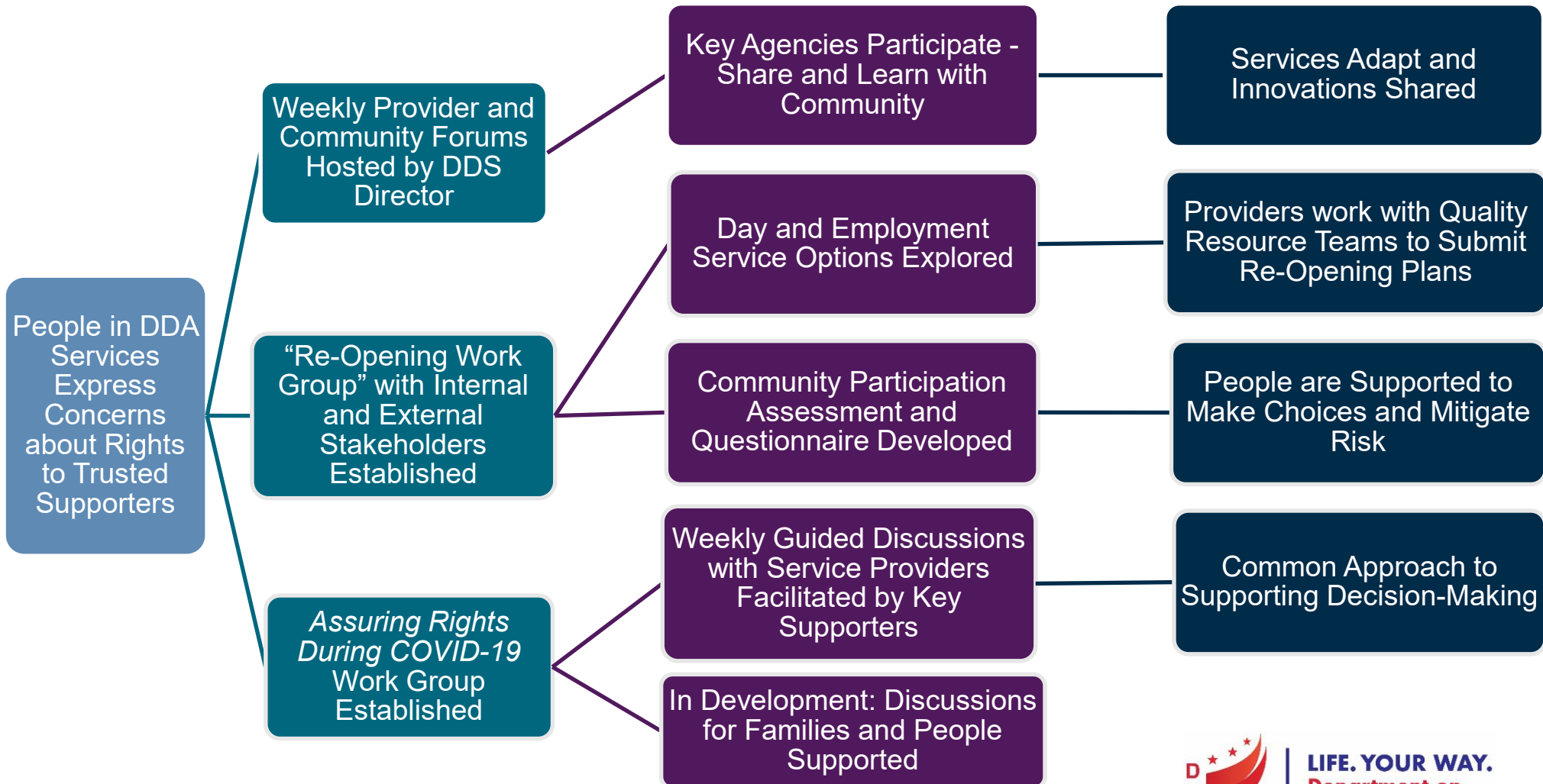
WHAT AM I GOOD AT OR INTERESTED IN?
List things that you've been told you do well, or you feel good about. What do you do that you are proud of or think is important? What would you like to learn more about or try? For example - you're a "people person" or like helping others.

WHY IS IT IMPORTANT TO ME TO WORK?
List reasons you want to get a job or have a career. What are your thoughts on working? It could be you want to make money to have or do the things you want, or because you want to have a meaningful way to spend your days.

WHAT DO I NEED TO HELP ME FIGURE OUT WHAT I WANT TO DO?
List supports that are helpful to you and what is not. What specific support do you need to figure out what kind of job you would like and be good at? What do others need to know to best be able to help you explore jobs/careers?



Coordinated Culture of Support: Public Health Emergency Case Study



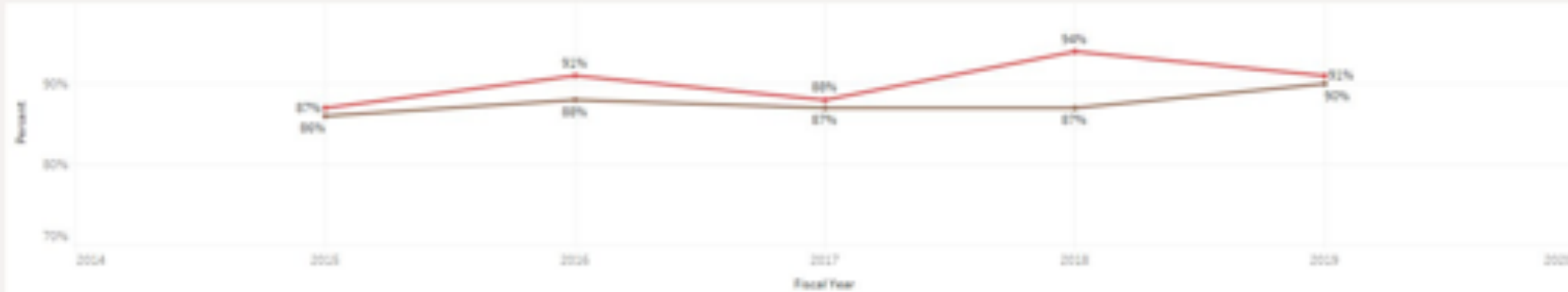
Improving Lives through Supports and Services that Foster Self Determination

The Missouri DDD Perspective



NCI Adult In-Person Survey: Data on Choice

Chooses or has Help Deciding What to Buy or has Set Limits on What to Buy with their Spending Money
 ("Person decides" and "person has help choosing what to buy or has set limits" responses only)



Chooses or has Help Deciding their Daily Schedule
 ("Person decides" and "person has help deciding" responses only)



Chose or had Some Input in Choosing Where They Live *(if Not Living in the Family Home)*
 ("Person made the choice" and "person had some input" responses only)



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Using NCI Data: Missouri's *Empowering through Employment* Initiative

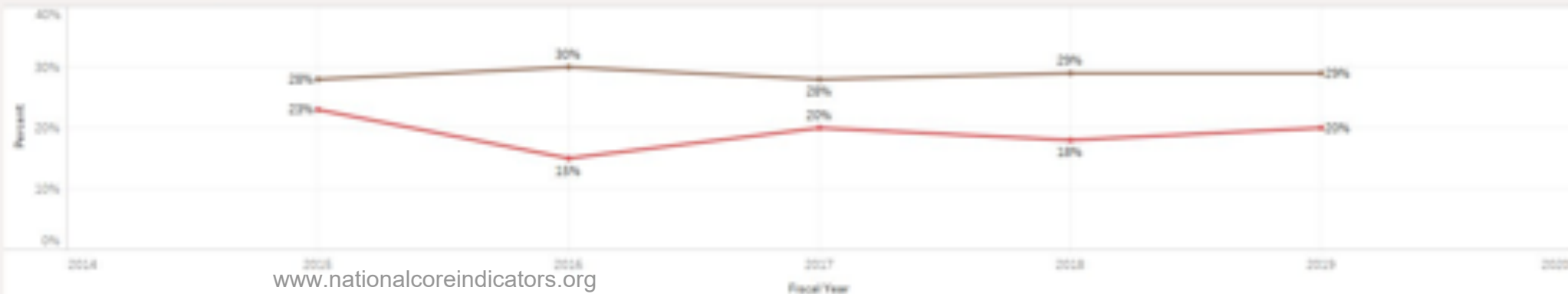
Has a Paid Job in the Community
("Yes" responses only)



Wants a Paid Job in the Community (among those who do not have a job)
("Yes" responses only)



Has Community Employment as a Goal in their Service Plan
("Yes" responses only)



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Areas of Influence

Often, we focus training and tools for the individual and their family, when we need to also have customized training for the other areas of support.



Focus on Support Coordination Training

Missouri Support Coordination Core Competencies

The MO SC Core Competencies were developed from a variety of resources in partnership between UMKC-IHD, the Division of Developmental Disabilities, and the Support Coordination Capacity Building Advisory Group representing individuals with IDD, families, support providers, and targeted case management entities. The competencies were developed to ensure person-centered, consistent and quality support coordination across the state. The DDD uses the competencies as overall guidance when working with entities that are contracted to provide support coordination, as well as training state employed support coordinators.


Missouri SC Core Competencies		
Core Competency: FOUNDATIONAL VALUES, BELIEFS, AND SKILLS		
Support Coordinators are knowledgeable and adaptable professionals, demonstrating ethical behavior and professionalism across all core competency areas.		
Case Management Requirements	Sub-Categories	Knowledge, Skills, and Attitudes
DDD TCM Manual: The single most important element of quality support coordination is building relationships. When strong relationships are developed and trust exists between all people involved with the individual supported, the quality of supports and services improves. Yet, building relationships is not a separate and distinct activity; it is integral to each function the support coordinator performs.	<p>Disability Values and Knowledge: Understand and articulate the philosophies and practices related to supporting individuals with disabilities, and the various systems that establish and ensure services and supports align with these paradigms</p> <p>Self-Awareness: Recognize and respond to any personal or professional values or behavior that may interfere with the ability to provide supports in an ethical, unbiased, and culturally competent manner</p> <p>Professionalism: Continually develop and utilize personal and professional skills in a responsible and responsive manner to meet both regular and unexpected work tasks</p>	<ul style="list-style-type: none"> Disability Values/Paradigms: Integrate the philosophical values related to supporting persons with disabilities into all core competency areas Disability Service Infrastructure: Understand the formal services and service structures at federal, state, and local levels, including both internal agency and external service delivery practices and standards Best Practice: Identify and implement evidence based intervention approaches to promote well-being in all life domains Ethics: Behave and practice ethically, adhering to all relevant laws and regulations and respecting the rights of the individual supported Cultural-Competence: Respect the cultural needs and preferences of each individual, to include the use of verbal and written communication that is understandable to all Self-Awareness: Recognize personal bias with work tasks or relationships Professional Judgment and Critical Thinking: decision-making skills to prioritize work from appropriate others when needed Professional Development: Maintain capacities through accessing opportunities Personal Professionalism: Demonstrate

Charting the LifeCourse™ Ambassadors Series

Series Information

Desired Outcome for Ambassadors	Enhance the practice of Support Coordination and enhance the culture of MO DDD to be more person and family centered
Purpose/Focus of Series	<ul style="list-style-type: none"> Personal impact Impact for professional role/organization Impact for _____
Roles of Ambassadors (at organization, on project, on team, etc.)	Support Coordinators, SC Supervisors, Regional Office Leadership
Coaching Call Format	<ul style="list-style-type: none"> Group all together? Individual Zoom Invites?

Individual Support Plan Guide




FACILITATING INDIVIDUALIZED SERVICES AND SUPPORTS

Learning how to write supports and services that are self-determined

Missouri, 01-20-18

2.1.1 Course Introduction



UNDERSTANDING INDIVIDUAL AND FAMILY

This course provides a deeper insight into understanding the person not only in the context of their family, but also their values, culture, and past experiences. In the course, you will watch a video lecture on this topic. Then, you will select a LifeStory Learning Scenario to apply to the tool for this course, a Relationship Map. Below are the learning objectives and core competency connections for the course.

Course Outline

Learning Milestones	Estimated Time to Complete
Pre-Knowledge Check	3 minutes
Video Lecture	10 minutes
Learning Activities	20-30 minutes
Post-Knowledge Check	3 minutes
Estimated Time to Complete Course	45 minutes

Course Learning Objectives

1. Recognize the relationship and context between a person and their family
2. Describe how values, culture and diversity impact work with the person and their family and team
3. Practice using a Relationship Map to engage on a deeper level and support planning

Course + Competency Connection

Employment Toolkit Coming Soon!



Supported Decision Making and Employment in Missouri

Through the Lens of Charting the LifeCourse



Missouri's Journey

- Missouri's Working Interdisciplinary Network of Guardianship Stakeholders (MO-WINGS)
- Missouri Consortium on Supported Decision Making
- Changes to Missouri's Guardianship and Conservatorship Code (Chapter 475 RSMO)
- Widespread adoption of the Charting the LifeCourse Framework

Summary of 2018 Statute Revisions to Missouri Guardianship Code

- Petition for appointment of guardian **must now state factual basis for petitioner's conclusion of incapacity**, including **incidents and specific behaviors**
- Court must now consider if respondent's needs can be met by a **less restrictive alternative** before appointing a guardian (ie-DPA, trust, representative payee, **SUPPORTED DECISION MAKING AGREEMENTS**, services or assistive tech, temporary emergency guardian ad litem, limited guardian or conservator)
- **Required specific findings** (ie- retention of rights to vote, drive or marry; placement, or management of other essential needs)
- Clear and convincing evidence of incapacity, and **evidence that needs cannot be met by a less restrictive alternative**

Opportunities for Life Experiences

Dignity of risk is the right to take risks when engaging in life experiences, and the right to fail in those activities.

- Life experiences are how we move our trajectory
- How does someone learn to stay safe if they are not given opportunities to try and fail?
 - Over-protection can result in lowered expectations, learned dependency, low self-esteem and underachievement

Finding a Balance



What Decision Making Supports are Needed?

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 need support with an administrator	I need support with my decision	I need assistance 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 set a budget or know how much money I want to spend?			
Am I able to manage the eligibility benefits I receive?			
Do I make sure to eat & taking my meds or using it for themselves?			
Healthy Living			
Do I choose when to go to the doctor or dentist?			
Do I decide/choose 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? (checkups, routine screening, working out, vitamins)			
Can I make medical choices in serious situations? (surgery, big injury)			
Can I make medical choices in an emergency?			
Can I take medications as directed or follow a prescribed diet?			
Do I know the reasons why I take my medication?			
Do I understand the consequences of refusing medical treatment?			
Can I seek others and ask medical help for serious health problems?			
Do I make choices about birth control or pregnancy?			
Do I make choices about drugs or alcohol?			
Do I understand health consequences associated with choosing high risk behaviors? (substance abuse, exercising, high-risk sexual activities, etc.)			
Do I decide when, what, and what to eat?			
Do I understand the need for personal hygiene and dental care?			

Continue on back >

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CHARTING THE LIFECOURSE | EXPLORING DECISION-MAKING SUPPORTS

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 need support with an administrator	I need support with my decision	I need assistance to decide for me
Social & Spirituality			
Do I choose where and when (and if) I want to practice my faith?			
Do I make choices about what to do and who to spend time with?			
Do I decide if I want to date, and choose who I want to date?			
Can I make decisions about marriage? (I want to marry, and who)			
Can I make choices about sex, and do I understand consent and permission in regard to sexual relationships?			
Safety & Security			
Do I make choices that help me avoid common environmental dangers? (fires, stray objects, hot liquid, poisonous products, etc.)			
Do I make plans in case of emergencies?			
Do I know and understand my rights?			
Do I recognize and get help if I am being treated badly? (physical, emotional, or sexually abused, or neglected)			
Do I know who to contact if I feel like I'm in danger, being exploited, or being treated unfairly? (police, attorney, trusted friend)			
Community Living			
Do I decide where I live and who I live with?			
Do I make safe choices around my home? (turning off stove, locking doors)			
Do I decide about how I keep my home or room clean and clutter?			
Do I make choices about going places: travel to when? (work, bank, stores, church, friends' homes)			
Do I make choices about going places: don't travel to often? (doctor appointments, special events)			
Do I decide how to get to the place I want or need to go? (walk, eat a train for a ride, bus, car, or service)			
Do I decide and direct what kinds of support I need or want and choose who provides those supports?			
Advocacy & Engagement			
Do I decide who I want to represent my interests and support me?			
Do I choose whether to vote and who I vote for?			
Do I understand consequences of making decisions that will result in me committing a crime?			
Do I tell people what I want and don't want? (attorneys, my sign, service, and tell people how I make choices)			
Do I agree to and sign contracts and other formal agreements, such as powers of attorney?			
Do I decide who I want information shared with? (family, therapists)			

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Exploring Decision Making Supports for Employment



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



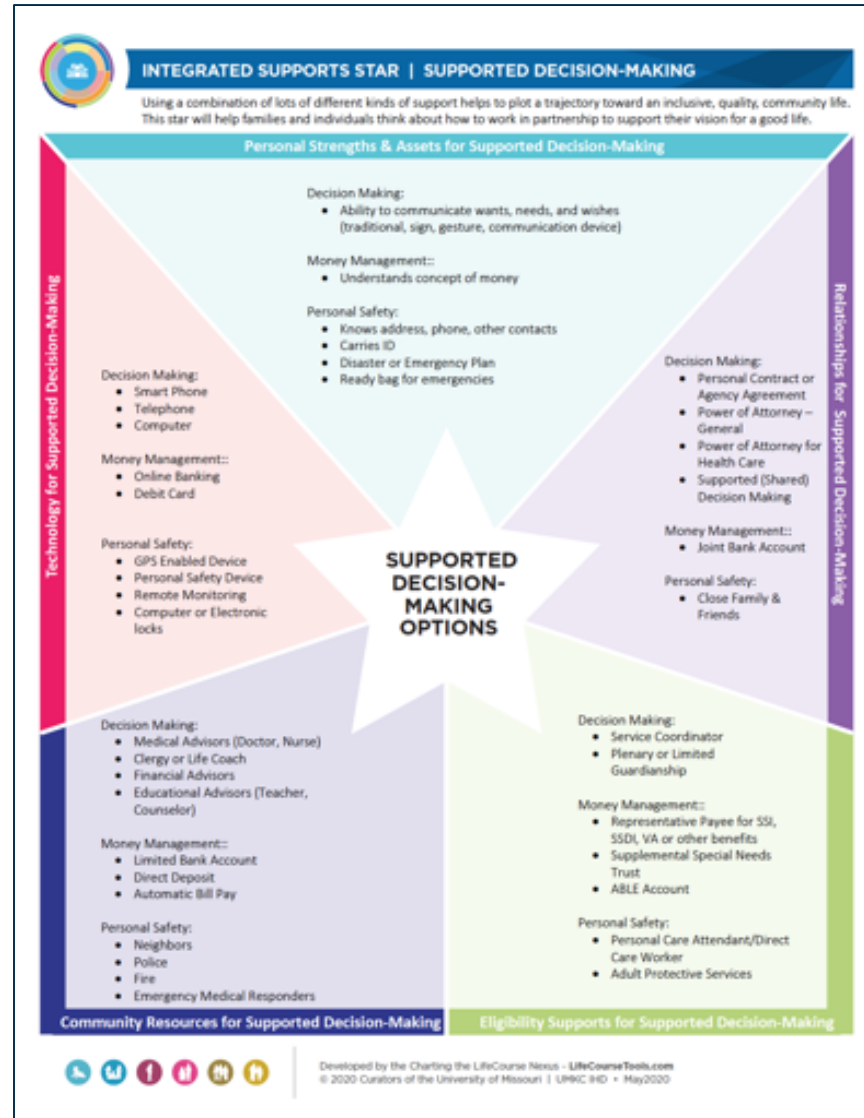
I need someone to decide for me



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?			

Charting the LifeCourse Integrated Supports “Starter Star” for SDM



Meet Candace

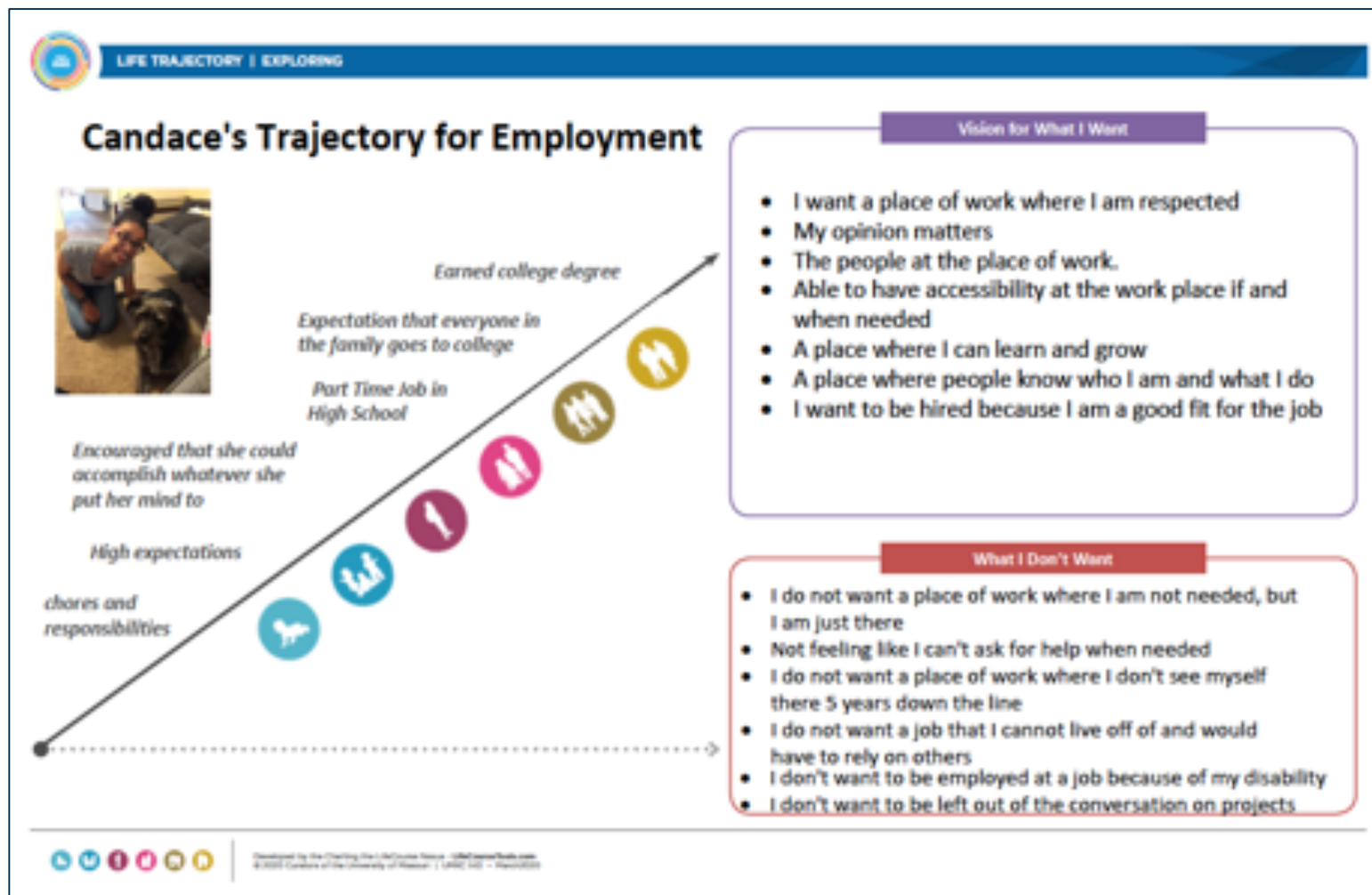


Candace makes her own decisions

When she needs support, her mom, Karen, helps by listening, helping think through her options, giving advice



Candace's Employment Trajectory



COVID-19

Daily Life and Employment

Healthy Living

Respite

Supported Decision-Making

LifeCourse Framework

Foundational Tools

Exploring the Life Domains

Exploring the Life Stages

Integrated Support to Elders



Exploring the Life Domains

Supported Decision-Making

Being decisions and choices you have through life, with support when you need it.



Supported decision-making is when having people, together of age or ability, make their own decisions by using a variety of integrated supports, including self or peer help, task learning, technology, supports, and supports. The supports might help a person understand what their choices are, what their choices mean, what their choices will do for them, communicate their own decisions to others, or help them with decision-making skills. Just because someone has a certain disability or diagnosis, or is experiencing memory or other challenges, doesn't mean they cannot express preference or make choices and decisions with help provided. It's really about an individual's needs and abilities for choices or how they, family, professionals, or other services in having an ability to make their own choices.

The National Transition and Support Center helps a person, family, or a professional understand what supports might help someone make their own decisions and how to get help, and also see the model supports.

Getting Started

Explore some of our many guides and supported decision-making support tools for more information and how to use supports and self supports.



Tool for Exploring Decision-Making Supports

Explore the areas of life where you can make choices and decisions, and decision-making self-support might be needed for making your own decision-making choices.



Transitionary for Supported Decision-Making

Organize and make a plan for decision-making, or help an adult to get started with an adult decision or help in the plan, and make their own decision.



Integrated Support Plan for Supported Decision-Making

Use this tool to consider a variety of supports for helping with understanding options, communicating decisions, or following through with choices and decisions.

Resources on lifecoursetools.com



www.LIFECOURSETOOLS.com

Discussion



Appendix

Presenter Bios and Contact Information

Erin Leveton



- Director, Alvarez and Marsal, Public Sector Services
- Former Deputy Director for Quality and Performance Management Administration for the District of Columbia
- 20+ years of experience in disability law and policy

Contact Erin

Erin Leveton, J.D.

Director

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<https://www.alvarezandmarsal.com/industries/public-sector>

Jane St. John



- Mom of 3 sons, “Ben’s mom”
- National Community of Practice on Supporting Families Team
- Co-developer of the CtLC framework and tools
- Trainer/Coordinator: SDM

Contact Jane

Jane St. John

University of Missouri Kansas City

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Charting the LifeCourse

(816) 235-5684

stjohnj@umkc.edu

Jill Shoemate



- Director of State Support Coordination and Community Living Coordinators
- Charting the LifeCourse Ambassador
- 10+ years of experience in Support Coordination



Contact Jill

Jill Shoemate

Director of State Support Coordination and
CLCs

Missouri Division of Developmental Disabilities

(573) 406-6646

Jill.Shoemate@dmh.mo.gov



Emily Ornstein



- Person-Centered Thinking
Project Manager
- DDS Liaison to State Supporting Families Community of Practice and Family Support Council
- Trainer/Coordinator for Supported Decision-Making training for interagency staff and people supported

Contact Emily

Emily Ornstein

Person Centered Thinking Project Manager

State Office of Policy Planning and Innovation

Department on Disability Services

emily.ornstein@dc.gov

202-730-1687

Morgan Whitlatch



- Lead Project Director of NRC-SDM
- Legal Director of Quality Trust and its Jenny Hatch Justice Project
- Project Director under Cooperative Agreements for NCD's reports on guardianship and alternatives (2018, 2019)

Contact Morgan

Morgan K. Whitlatch, J.D.

Legal Director, Quality Trust

Lead Project Director, NRC-SDM

mwhitlatch@dcqualitytrust.org

202-459-4004

Licensed to practice law in DC and MD

Acronyms

Acronyms

- CoP: Community of Practice
- CtLC: Charting the LifeCourse
- DDD: Division of Developmental Disabilities
- DDS: Department on Disability Services
- DPA: Durable Power of Attorney
- EFSLMP: Employment First State Leadership Mentoring Program
- FSC: Family Support Council

Acronyms

- HCBS: Home and Community Based Services
- HHS: Health and Human Services
- IDD: Intellectual and Developmental Disability
- LTSS: Long Term Services and Supports
- MO-WINGS: Missouri's Working Interdisciplinary Network of Guardianship Stakeholders
- NCI: National Core Indicators

Acronyms

- NRCSDM: National Resource Center on Supported Decision-Making
- RSMO: Revised Statutes of Missouri
- SDM: Supported Decision-Making
- SF CoP: Supporting Families Community of Practice

Resources

District of Columbia: Resources

- Department on Disability Services Supported Decision Making Rights - Forms and Resources (including train-the-trainer webinar):
<https://dds.dc.gov/node/1350336>
- Department on Disability Services Community Participation Assessment and Questionnaire:
<https://dds.dc.gov/publication/dds-operating-status-during-covid-19-emergency>
- Employment and Discovery Toolkit:
<https://dds.dc.gov/sites/default/files/dc/sites/dds/publication/attachments/Employment%20%26%20Discovery%20Toolkit%207-11-18.pdf>
- Family Support Council Decision-Making Project:
<https://dds.dc.gov/sites/default/files/dc/sites/dds/publication/attachments/DM%20FSC%20recommendations%204.19.pdf>
- National Resource Center for Supported Decision-Making:
<http://www.supporteddecisionmaking.org>
- DC Supporting Families Community of Practice Supported Decision-Making Trajectory:
<https://dds.dc.gov/publication/supported-decision-making-trajectory>

Alternate Format Copies Available Upon Request

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Thank You!