Supporting Self-Determination and Employment through Supported Decision-Making
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
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.

Source: Council on Quality and Leadership
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)

Slide Credit: Quality Trust for Individuals with Disabilities
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

State SDM Legislation and/or Resolutions

- Introduced
- Enacted
- Pending

As of 9/1/2020

Visit www.SupportedDecisionMaking.org to learn more!
More U.S. State Trends in SDM

- **National Resource Center for SDM State Grant Program**
  - 18 projects so far
  - DC, DE, FL, GA, IN, ME, MN, MS, NC, NV, NY, OR, SC, TN, WI

- **Court Orders and Decisions**
  - Examples: DC, FL, IN, KY, MA, ME, MN, NV, NY, PA, VA, VT, and more!

- **SDM Pilots**
  - Examples: AK, CA, FL, GA, IN, KY, MA, ME, NY, VT, TX, and 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)
- Uniform Law Commission (2017)
- 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
“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
Coordinated Culture of Support: Public Health Emergency Case Study

People in DDA Services Express Concerns about Rights to Trusted Supporters

Weekly Provider and Community Forums Hosted by DDS Director

"Re-Opening Work Group" with Internal and External Stakeholders Established

Assuring Rights During COVID-19 Work Group Established

Key Agencies Participate - Share and Learn with Community

Day and Employment Service Options Explored

Community Participation Assessment and Questionnaire Developed

Weekly Guided Discussions with Service Providers Facilitated by Key Supporters

In Development: Discussions for Families and People Supported

Services Adapt and Innovations Shared

Providers work with Quality Resource Teams to Submit Re-Opening Plans

People are Supported to Make Choices and Mitigate Risk

Common Approach to Supporting Decision-Making
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
- Chooses or has Help Deciding their Daily Schedule
- Chose or had Some Input in Choosing Where They Live

Source: www.nationalcoreindicators.org
Using NCI Data: Missouri’s *Empowering through Employment* Initiative

- Has a Paid Job in the Community
  - (*Yes* responses only)
  - Graph showing trends from 2014 to 2020 for Missouri (MO) and NCI.

- Wants a Paid Job in the Community (among those who do not have a job)
  - (*Yes* responses only)
  - Graph showing trends from 2014 to 2020 for Missouri (MO) and NCI.

- Has Community Employment as a Goal in their Service Plan
  - (*Yes* responses only)
  - Graph showing trends from 2014 to 2020 for Missouri (MO) and NCI.
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

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

Dignity of Risk; Life Experiences; Self-Determination

Health and Safety
What Decision Making Supports are Needed?

**Daily Life & Employment**

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<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Not Applicable</th>
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<tbody>
<tr>
<td>Can I decide if and when I go to work?</td>
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<td>Can I plan what I do in my day?</td>
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<td>Can I make decisions about money?</td>
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<td>Can I make decisions about transportation?</td>
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<td>Can I make decisions about medical treatments?</td>
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<td>Can I make decisions about safety and security?</td>
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<td>Can I make decisions about leisure and recreation?</td>
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<td>Can I make decisions about social and community activities?</td>
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<td>Can I make decisions about advocacy and engagement?</td>
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**Healthy Living**

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<th>Question</th>
<th>Yes</th>
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<td>Can I choose when to go to the doctor or dentist?</td>
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<td>Can I choose who to see?</td>
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<td>Can I make choices about health care providers?</td>
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<td>Can I make choices about the type of medical treatment I receive?</td>
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<td>Can I make choices about the type of medication I receive?</td>
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<tr>
<td>Can I make choices about the type of health insurance I receive?</td>
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<td>Can I make choices about health care providers who I receive health care from?</td>
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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.

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

Candace's Trajectory for Employment

- Earned college degree
  - Expectation that everyone in the family goes to college
- Part Time Job in High School
- Encouraged that she could accomplish whatever she put her mind to
- High expectations
- chores and responsibilities

Vision for What I Want
- I want a place of work where I am respected
- My opinion matters
- The people at the place of work.
- Able to have accessibility at the work place if and when needed
- A place where I can learn and grow
- A place where people know who I am and what I do
- I want to be hired because I am a good fit for the job

What I Don’t Want
- I do not want a place of work where I am not needed, but I am just there
- Not feeling like I can’t ask for help when needed
- I do not want a place of work where I don’t see myself there 5 years down the line
- I do not want a job that I cannot live off of and would have to rely on others
- I don’t want to be employed at a job because of my disability
- I don’t want to be left out of the conversation on projects
Resources on 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

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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

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Jill Shoemate

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

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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

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Person Centered Thinking Project Manager
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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.
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Lead Project Director, NRC-SDM
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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
- 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!