Missouri’s Journey to Supported Decision Making

June 11, 2019
About Jane....

- Mom of 3 sons, “Ben’s mom”
- Partners in Policymaking Graduate (Missouri 1999)
- UMKC-Institute for Human Development, UCEDD
  - National Community of Practice on Supporting Families Staff
- Co-developer of the CtLC framework and tools
- Trainer/Coordinator of activities focusing on supported decision making
Every person can make choices and has a right to make decisions

Don Hoyle,
The Arc of Michigan
Missouri Guardianship: Understanding Your Options & Alternatives 2009 and 2013

Partnership between:
- UMKC-IHD, UCEDD
- Missouri Protection and Advocacy
- Missouri Developmental Disabilities Council
- People First of Missouri
Mo Guardianship: Understanding Options and Alternatives

- Developed and launched in 2009/2013
- Workshops for families, self-advocates, and professionals
- Promoted making informed decisions about guardianship options and alternatives with emphasis on supported decision making

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Missouri's Working Interdisciplinary Network of Guardianship Stakeholders

Welcome to MO-WINGS

History

Missouri's Working Interdisciplinary Network of Guardianship Stakeholders (MO-WINGS) has been meeting for several years to review and propose revisions to Chapter 475.RSMo — Missouri’s Guardianship and Conservatorship law. MO-WINGS was established in part based upon Recommendation 5.2 of the 3rd National Guardianship Summit, October 2011 to have an interdisciplinary group rather than just attorneys and judges address issues of guardianship and conservatorship.

MO-WINGS has been chaired by Emily Hartley of the Missouri Developmental Disabilities Council; William S. “Vim” Horn, of the UMKC Institute for Human Development; David English, the William F. Fratcher and Edwin L. Jenkins Professor of Law, University of Missouri School of Law (formerly chair of the Missouri Bar Protection and Trust Committee), and the late Regent’s ‘Wing’ Turnbull, a private practice attorney (former chair of the Missouri Bar Elder Law Committee.)

Members of MO-WINGS have included representatives of persons with disabilities, parents, family members, lay guardians and conservators, service providers, AARR NAMI Alzheimer’s Association, Missouri Developmental Disabilities Council, Missouri Bar Probate and Trust and Elder Law Committees, Missouri Association of County Developmental Disability Services, public administrators, social workers, nurses, psychologists, Missouri Protector and Advocacy, lay guardians, advocacy groups, long-term care ombudsmen, University of Missouri-Columbia Center for Health Ethics, Departments of Mental Health and Health and Senior Services, and Area Agencies on Aging with input from judges and national experts.
Summary of Statute Revisions to Guardianship Code

Changes to Chapter 475 RsMO, Mo’s Guardianship and Conservatorship Statute

These changes are a result of the passage of SB 806, Effective August 28, 2018
Summary by Annie Ebert and David English 6-18-18
Additions by Dolores Sparka 6-25-18
Further Revision by David English 7-10-18
Summary of Statute Revisions to Guardianship Code

- Appointment Priority (Court to appoint suitable relative over unrelated 3rd party)
- Background checks
- Co-Guardians
- Petition for appointment of guardian for adult must now state factual basis for petitioner’s conclusion of incapacity, including incidents and specific behaviors of respondent that support why sought
- Respondents rights at hearings
Summary of Statute Revisions to Guardianship Code

- 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 (including 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
Guardian Powers & Responsibilities

- **NEW** - 10 days notice before sale of real or tangible personal property
- **NEW** - Specific guardian powers and requirements
  - May *only* exercise authority as required by ward’s limitation
  - MUST encourage ward to participate in decisions to extent possible, and develop or regain capacity
Rights of the Ward

1. A guardian who acts in the best interests of the ward:

2. A guardian who is reasonably accessible to the ward:

3. Communicate freely and privately with family, friends, and other persons other than the guardian; except that, such right may be limited by the guardian for good cause but only as necessary to ensure the ward’s condition, safety, habilitation, or sound therapeutic treatment;

4. Individually or through the ward’s representative or legal counsel, bring an action relating to the guardianship, including the right to file a petition alleging that the ward is being unjustly denied a right or privilege granted by this chapter, including the right to bring an action to modify or terminate the guardianship under the provisions of section 476.083;
Rights, continued

5. The least restrictive form of guardianship assistance, taking into consideration the ward’s functional limitations, personal needs, and preferences;

6. Be restored to capacity at the earliest possible time;

7. Receive information from the court that describes the ward’s rights, including rights the ward may seek by petitioning the court;

8. Participate in any health care decision-making process.
Adult Ward Can Petition Court for the Right To:

1. Contract to marry or to petition for dissolution of marriage;
2. Make, modify, or terminate other contracts or ratify contracts made by the ward;
3. Consent to medical treatments;
4. Establish a residence or dwelling place;
5. Change domicile;
6. Bring or defend any action at law or equity, except an action relating to the guardianship; or
7. Drive a motor vehicle if the ward can pass the required driving test.
So, What’s NEXT?
Missouri’s Vision & Trajectory for Supported Decision Making

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MISSOURI SYMPOSIUM ON SUPPORTED DECISION MAKING

AGENDA OUTLINE:

9:30-10 am - Introduction
  • Overview of day – Setting realistic expectations
  • Brief definition of SDM
  • Identification of and commitment to 3 Principles

10-11:00 am - Identifying strengths and potential for success
  • What must happen in order for our effort to be considered success? What should SDM look like (broad strokes)? What are things we do well that can make that happen? Where should SDM be used? Who needs to be part of the discussion to accomplish that? One year from now, what do we want to say we accomplished? Over the next year, what are some specific things we can do, or specific examples of opportunities we have/people and professionals we can talk to, to make that happen? How do we translate our strengths and opportunities into action?

11-12:15 pm - Identifying challenges and obstacles to success
  • What must not happen? What are the dangers of SDM? What are the biggest obstacles to making SDM accepted and available? What partners do we need that we don't have now? How will we define failure? What are some specific examples of things we must avoid? What mistakes have been made before that we can't repeat? Is anyone “against us”? If so, why and what can we do to try to work with them?

12:15-1:00 pm - Lunch

1:00-2:00 pm - Setting priorities
  • What have we discovered about SDM in Missouri? How do we prioritize where to begin?

2:00-3:15 pm - Next steps
  • How do we enhance successes and overcome the challenges and obstacles to implementing SDM in Missouri? What are some “products” the task force should create – educational materials, pilot projects, outside-of-the-box thoughts on ways to increase knowledge, access, and use of SDM throughout Missouri, etc.?

3:15-4:00 pm - Report back and discuss how to move forward

SYMPOSIUM HOSTS

Arc of Missouri
Lafayette County Board of Services
Midwest Advocacy for Disability Rights (MADR)
Missouri Developmental Disabilities Council (MODDC)

Missouri Association of County Developmental Disabilities Services (MACDDS)
Missouri Protection and Advocacy (MO P&A)
People First of Missouri (PFMO)
UMKC Institute for Human Development (UMKC IHD)
3 Guiding Principles

Agreed upon at the Symposium

1. Recognize and respect that everyone has an equal right to make their own decisions, regardless of their diagnosis or functional challenges.

2. Be respectful of the various opinions and deeply held beliefs that have led parents and advocates to choose different options for decision-making support, including SDM.

3. Promote the use and development of practices that will provide people in need of support with individualized decision-making assistance in a way that imposes the absolute minimum restriction of rights.
Findings & Recommendations

- Customized education and training programs on SDM theory, practice, and benefits
- SDM materials
- Changes in guardianship numbers
Next Steps

- Review and expand existing projects and resources advancing SDM
- Develop new projects and resources that will advance SDM
- Identify, acknowledge, and overcome challenges and obstacles to implementing SDM in Missouri
Meeting Announcement

You are receiving this meeting invitation because you attended the Missouri SDM Symposium in Columbia, MO, on September 12, 2018 and signed up to be part of the Missouri SDM Consortium. At that time, over 100 participants agreed to continue the work we began.

At the Symposium, the group identified a broad set of ideas and recommendations that have now been summarized into a consensus document that will be used at the meeting. Please see attached document.

When: April 4, 2019 – 9:30am to 3:30pm
Where: Riechmann Indoor Pavilion
2300 E. Walnut St., Columbia, MO 65201
Stephens Lake Park - map

Why: To continue work begun at the SDM Symposium last September

What will be accomplished: The purpose of this Consortium meeting will be to take the broad-based recommendations contained in the document and develop an action plan.

Cost for Lunch (optional - you may bring a lunch or leave to buy one):
- Individuals with disabilities and family members - FREE
- Professionals - $20

We ask all participants to register to attend at: https://mo-sdm-consortium1.eventbrite.com
In order to receive a lunch, you must register by March 31, 2019.

This meeting of the Consortium is supported by:
- Missouri Developmental Disabilities Council
- Missouri Protection & Advocacy
- UMKC Institute for Human Development, a University Center for Excellence in Disabilities

For questions, please contact Vim Horn at hornw@umkc.edu.
The Consortium:

- Identified and prioritized strategies and tools to inform Missourians about SDM
- Broke into work groups to continue progress between meetings
- Will reconvene in five to six months to share what has been done and plan next steps
Pilot: Health Care & SDM
Charting the LifeCourse Health Care Preferences and Supported Decision Making for People with IDD

- Enhance the partnership between medical professionals, adults with IDD, family members, and disability providers that supports informed choice and SDM practices on health care decisions
- Increase knowledge and skills by providing training and coaching on SDM
- Facilitate effective communication with each target group in the St. Joseph, Missouri area
- Develop and disseminate Charting the LifeCourse Healthcare Training and Coaching Toolkit

Established in 2002, WITH Foundation (formerly known as Special Hope Foundation) is a private foundation. The Foundation’s initial grantmaking benefited the disability community. In 2011, the Foundation began to focus its support on organizations and projects that promote the establishment of comprehensive and accessible health care for adults with intellectual and developmental disabilities. Currently, the Foundation gives out around $750,000 each year and has provided (in total) more than $7 million in funding support.
Project Objectives

- **Self-Advocates** demonstrate increased skills and confidence for making decisions in healthcare settings.

- **Family members and disability staff** demonstrate increased skills and knowledge of the Supported Decision Making (SDM) process.

- **Medical Professionals** demonstrate increased knowledge of IDD as well as increased skills and confidence to partner in the SDM process that leads to informed consent.

- Develop a Charting the LifeCourse HealthCare Preferences, Supported Decision Making Training and Coaching Toolkit.
Phase One – Educational Presentations

- Mosaic Life Care, for health care professionals
  - One hour sessions
  - At the clinics and hospital
- I/DD Professionals (provider staff, support coordinators), self-advocates, and families
Phase 2- Coaching (with DD professionals, self-advocates, family members)

- Four coaching sessions offered to mixed audiences in person that included:
  - Exploring a Vision for Overall Health
  - Planning for Day-to-Day Healthy Living Goals
  - Identifying Specific Supports for Health Decision Making
  - Preparing for Doctor Visits and Medical Procedures

- Sessions were conducted live/in person at monthly intervals
- Participants were encouraged to attend as “teams”
Possible Health/Decision Making Team Roles

- Help with **understanding** the visit or their options/choices
- Help **communicate** with the doctor, nurse, care coordinator, or other medical staff
- May be responsible for helping **implement** the physician recommendations or treatment plans (taking meds, special diets, etc.)
- Or, Legal decision maker
What Does a Supporter Do?

- **Support to understand** their medical situation and their choices
  - Information
  - Advice
- **Support to communicate** their preferences
  - Communication
- **Support to follow through** on their decision or doctor’s recommendations
  - Reminders and logistics

ACLU Disability Rights Program [www.aclu.org/issues/disabilityrights/supported-decision-making](http://www.aclu.org/issues/disabilityrights/supported-decision-making)
Results

- Total of 120 people completed pre/post, including professionals from inpatient, outpatient, mental health, psychiatry, nursing, etc.

- Healthcare Professionals reported significant differences in knowledge and confidence surrounding guardianship options and alternatives, supporting an individual’s healthcare goals, promoting teamwork for decision making and where to find resources regarding supported decision making.

- Direct support professionals and families reported fewer changes in the knowledge and skills needed for guardianship and partnering with medical professionals for decision making.
<table>
<thead>
<tr>
<th><strong>IDENTIFYING ALTERNATIVES TO GUARDIANSHIP</strong></th>
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<tbody>
<tr>
<td><strong>Name of Individual:</strong></td>
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<tr>
<td><strong>Relationship to individual (circle one):</strong></td>
</tr>
<tr>
<td><strong>How long have you known the individual?</strong></td>
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This checklist is a tool designed to be used for the purposes of the training program.

**MO Guardianship**

Understanding Your Opinions & Alternatives.

It is designed to assist with identifying a person’s ability to make decisions and manage key areas of the individual’s life. It is intended to assist with exploring alternatives and less restrictive options to plenary or full guardianship.

The questions listed below are just starters and are suggested to provide a broad determination of what a person should (or should not) do in their unique circumstances.

### Employment

- **Can the person make and communicate choices in regard to employment?**
- **Can the person look for and find a job (go to employment agency, respond to ads, use contacts)?**
- **Can the person make and communicate choices in regard to employment?**

### Money Management

- **Is the person able to manage their money (i.e., meet financial commitments, such as rent)?**
- **Is the person able to manage their monetary benefit in the same way as others?**
- **Is the person able to identify and avoid financial exploitation?**

### Health & Nutrition

- **Does the person make decisions about where, when, & what to eat?**
- **Can the person follow a prescribed diet and/or take medications as directed?**
- **Does the person understand the need to maintain personal hygiene and dental care?**
- **Does the person understand the need to maintain personal hygiene and dental care?**

### Daily Life & Employment

- **Can the person make and communicate choices in regard to employment?**
- **Can the person look for and find a job (go to employment agency, respond to ads, use contacts)?**
- **Can the person make and communicate decisions regarding medical treatment, including understanding the consequences of not accepting treatment?**
- **Can the person understand health consequences associated with high-risk behaviors (substance abuse, overeating, high-risk sexual activities, etc.)?**

### Healthy Living

- **Does the person make decisions about where, when, & what to eat?**
- **Can the person follow a prescribed diet and/or take medicines as directed?**
- **Can the person understand the need to maintain personal hygiene and dental care?**
- **Can the person make and communicate decisions regarding medical treatment, including understanding the consequences of not accepting treatment?**

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Exploring Supported Decision Making

**Tool for Exploring Decision Making Supports**

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

<table>
<thead>
<tr>
<th>Name of individual:</th>
<th>Name of person completing this form:</th>
<th>Relationship to individual (circle one): Self</th>
<th>Family</th>
<th>Friend</th>
<th>Guardian</th>
<th>Other:</th>
<th>How long have you known the individual?</th>
</tr>
</thead>
</table>

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 I want to work?  
- Can I look for and find a job (new acts, apply, use personal contacts)?  
- Do I plan what my day will look like?  
- 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 (credit card, electric, internet)?  
- Can 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 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 if I refuse medical treatment?  
- Can I alert others and seek 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, overeating, high risk sexual activities, etc.)?  
- Do I decide where, when, and what to eat?  
- Do I understand the need for personal hygiene and dental care?  

**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 (if 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 (traffic, sharp objects, hot stove, 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 (physically, emotionally 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 (policy, 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, having fire alarms, locking doors)?  
- Do I decide about how I keep my home or room clean and livable?  
- Do I make choices about going places! I travel to often (work, bank, stores, church, friends' homes)?  
- Do I make choices about going places! I don't travel to often (doctor appointments, special events)?  
- Do I decide how to get to the places I want or need to go? (walk, ask a friend for a ride, bus, cab, car service)?  
- Do I decide and direct what kinds of support I need or want and choose who provides those supports?  

**CITIZENSHIP & ADVOCACY**

- Do I decide who I want to represent my interests and support me?  
- Do I choose who to vote for and who I will 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 (verbally, by sign, device), 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, friends etc.)?  

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### UNDERSTANDING MY HEALTH CARE TEAM

<table>
<thead>
<tr>
<th>WHO</th>
<th>Relationship</th>
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<table>
<thead>
<tr>
<th>Formal Supports (Who are paid people that might be with you and what their role is at the visit)</th>
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</thead>
<tbody>
<tr>
<td>Paid Staff (PCA, DSP):</td>
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<tr>
<td></td>
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<tr>
<td>Residential/Provider Agency Staff:</td>
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<td></td>
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<tr>
<td>Other:</td>
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<thead>
<tr>
<th>Who Has Legal Authority (Place a check next to who has legal decision-making authority and identify the person)</th>
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<tbody>
<tr>
<td>___ I have Legal Decision-Making Authority for My Health Care</td>
</tr>
<tr>
<td>___ Guardian:</td>
</tr>
<tr>
<td>___ Circle one: Plenary(full) OR Limited</td>
</tr>
<tr>
<td>___ Conservator:</td>
</tr>
</tbody>
</table>

### UNDERSTANDING MY SUPPORT NEEDS

<table>
<thead>
<tr>
<th>Areas of Support for Medical Appointments/Events</th>
<th>What I Do/Need and Who Helps Me</th>
<th>Health Professional's Role In Supporting Me</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understanding what the medical professionals are saying, suggesting, recommending or instructing; helping me know my options, pros and cons</td>
<td>Who do I trust to help me understand and how do I communicate with them?</td>
<td>Writing down instructions, using photos or pictures to explain procedures or directions</td>
</tr>
<tr>
<td>Communicating my current situation, my decisions/choices, and responding to or asking questions of medical professionals</td>
<td>Who helps me communicate with the medical professionals (doctor/nurse/care coordinator)?</td>
<td>Repeat my answers back to me; ask me to “teach back” instructions; ask me questions</td>
</tr>
<tr>
<td>Following through with my medical choices, decisions, or following doctor/nurse/care coordinator’s instructions or treatment plan</td>
<td>Who helps with follow through (reminders, set up medications, checking in with me)?</td>
<td>Send out reminders by mail or text; follow-up appointments</td>
</tr>
</tbody>
</table>

Developed by the UMIC Institute for Human Development, UCEDD. More tools and materials at lifesourcetools.com October 2018

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**Tool for Understanding the Decision Making Support Needs and Team**
Today’s Health Care Visit

How do you prepare?
How do you remember what happened at the visit?
How do others know what happened at the visit?
How do you follow up?
# Life Trajectory Worksheet: Supported Decision Making

## What Do I Need to Make Good Choices and Decisions?

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<table>
<thead>
<tr>
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<tbody>
<tr>
<td><strong>What Helps Me Understand the Issues and My Options?</strong></td>
<td><strong>What Helps Me Communicate My Preferences, Choices, and Decisions?</strong></td>
</tr>
<tr>
<td>What helped in the past?</td>
<td>What helped in the past?</td>
</tr>
<tr>
<td>What do I need now?</td>
<td>What do I need now?</td>
</tr>
<tr>
<td><strong>What Helps Me Follow Through on My Choices and Decisions?</strong></td>
<td><strong>What Makes It Hard to Make Good Choices and Decisions?</strong></td>
</tr>
<tr>
<td>What helped in the past?</td>
<td>What were barriers in the past that made it hard for me to Understand, Communicate, or Follow Through with my choices and decisions?</td>
</tr>
<tr>
<td>What do I need now?</td>
<td>What needs to happen to avoid barriers that make it hard for me to Understand, Communicate, or Follow Through with my choices and decisions?</td>
</tr>
</tbody>
</table>

## Vision for What I Want

- **What decisions and choices do I want to make myself or with help from my supporters?**
- **My Overall Good Life**

## What I Don’t Want

- **What decisions and choices do I NOT want someone else making for me or without my input or approval?**
- **Overall NOT Good Life**

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Charting the LifeCourse Portfolio: Supported Decision Making

Name: ___________________________ Date: ___________________________

**Technology**
- How can I use technology to help me with making decisions?

**Personal Strengths & Assets**
- What are my assets and strengths that will help me with making decisions?

**Relationships**
- Who are people in my life that can help me with making decisions?

**Supporting My Decisions**

**What is important TO ME when making choices and decisions?**

**What do others think is important FOR ME when making choices and decisions?**

**What SUPPORTS do I need to help me with making choices and decisions?**
- What are specific supports that work well for me and what does not?
- How do I learn best?
- What helps me stay motivated?
- What is the best way to encourage me?

Access the Charting the LifeCourse framework and tools at lifecoursetools.com

Charting the LifeCourse Portfolio is a template of the UMHC IRD, UCEDD. More materials at lifecoursetools.com

March 2019
LifeCourse Integrated STAR: Supported Decision-Making

When a person turns 18, they are presumed competent to make decisions about their life. Sometimes, a person might need help making decisions and staying safe. This star shows some of the ways people can be supported to make their own decisions and be safe and secure while living an inclusive community life.

**Technology**
- Smart Phone
- Telephone
- Computer

**Money Management**
- Online Banking
- Debit Card

**Personal Safety**
- GPS Enabled Device
- Personal Safety Device
- Remote Monitoring
- Computer or Electronic locks

**Personal Strengths & Assets**
- Ability to communicate wants, needs, and wishes (traditional, sign, gesture, communication device)
- Money Management: Understands concept of money
- Personal Safety: Knows address, phone, other contacts, carries ID, Disaster or Emergency Plan, Ready bag for emergencies

**Decision Making Supports**
- Personal Contract or Agency Agreement
- Power of Attorney – General
- Power of Attorney for Health Care
- Supported (Shared) Decision Making

**Money Management**
- Joint Bank Account

**Personal Safety**
- Close Family & Friends

**Decision Making**
- Medical Advisors (Doctor, Nurse)
- Clergy or Life Coach
- Financial Advisors
- Educational Advisors (Teacher, Counselor)

**Money Management**
- Limited Bank Account
- Direct Deposit
- Automatic Bill Pay

**Personal Safety**
- Neighbors
- Police
- Fire
- Emergency Medical Responders

**Community Based**

Access the LifeCourse framework and tools at lifecoursetools.com
Developed by the UMKC Institute for Human Development, UCEDD. More tools and materials at lifecoursetools.com. SEPTEMBER 2016
The Right to Make Choices

Introduction to Supported Decision-Making

Do I HAVE to get Guardianship?

Supported Decision-Making Series
Introducing Ben

Charting the LifeCourse Portfolio: Exploring

Name: Ben St. John

What Do People Like and Admire About Me?

- I like to laugh and have fun
- My Tattoo
- I'm good at remembering songs
- I don't complain
- I am an Eagle Scout
- I volunteer at the Fire Dept

What Is Important to Me?

- My family
- Friends
- Staying busy
- Working at ES Fire
- Going to Library
- Going to Church
- My iPad
- Doing stuff with Matt

What Are The Best Strategies To Support Me?

- I need help getting my pills
- I need rides to go places
- I need help with food sometimes
- I need help remembering things
- Sometimes I forget how to do something or get somewhere
- I need somebody to drive me places
- I need help with my shower
**Tool for 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:** Ben

**Name of person completing this form:** Ben with help from Mom (Jane)

**Relationship to individual (circle one):** Self

**How long have you known the individual?** 28 years

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? [X] I can decide with no extra support
- Can I look for and find a job (read ads, apply, use personal contacts)? [X] I need support with my decision
- Do I plan what my day will look like? [X] I need someone to decide for me
- Do I decide if I want to learn something new and how to best go about that? [X] I need someone to decide for me
- Can I make big decisions about money? (open bank account, make big purchases) [X] I need someone to decide for me
- Do I make everyday purchases? (food, personal items, recreation) [X] I need someone to decide for me
- Do I pay my bills on time (rent, cell, electric, internet) [X] I need someone to decide for me
- Do I keep a budget so I know how much money I have to spend? [X] I need someone to decide for me
- Am I able to manage the eligibility benefits I receive? [X] I need someone to decide for me
- Do I make sure no one is taking my money or using it for themselves? [X] I need someone to decide for me

### HEALTHY LIVING

- Do I choose when to go to the doctor or dentist? [X] I can decide with no extra support
- Do I decide/direct what doctors, medical/health clinics, hospitals, specialists or other health care providers I use? [X] I can decide with no extra support
- Can I make health/medical choices for my day-to-day well-being? (check-ups, routine screening, working out, vitamins) [X] I can decide with no extra support
- Can I make medical choices in serious situations? (surgery, big injury) [X] I need someone to decide for me
- Can I make medical choices in an emergency? [X] I need someone to decide for me
- Do I understand the consequences if I refuse medical treatment? [X] I need someone to decide for me
- Do I understand medications as directed or follow a prescribed diet? [X] I need someone to decide for me
- Do I know the reasons why I take my medication? [X] I need someone to decide for me
- Do I understand the consequences if I refuse medical treatment? [X] I need someone to decide for me
- Can I alert others and seek medical help for serious health problems? [X] I need someone to decide for me
- Do I make choices about birth control or pregnancy? [n/a] Not applicable
- Do I make choices about drugs or alcohol? [X] I need someone to decide for me
- Do I understand health consequences associated with choosing high risk behaviors (substance abuse, overeating, high-risk sexual activities, etc.)? [X] I need someone to decide for me
- Do I decide where, when, and what to eat? [X] I need someone to decide for me
- Do I understand the need for personal hygiene and dental care? [X] I need someone to decide for me

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Ben’s SDM Supports

**Now**
- Carries ID
- Uses Debit Card
- Can call 911

**Future**
- Communicate wants & needs better
- Spend more time on his own
- Call 911 only if emergency

**Relationships**
- Joint bank account with mom
- Power of Attorney (mom & dad)
- SN Trust Committee (Matt, Zac, Ali, Mike, Tracy)

**Now**
- Remote Monitoring
- Learn to use FaceTime or Skype

**Future**
- Add more Power of Attorney successors
- Supported (shared) decision making

**Now**
- Automatic Bill Pay
- Direct Deposit
- Well known at: Library, church, Fire station, restaurants, stores, bus
- Community Based

**Future**
- Limited bank account
- Senior Center
- Meals on Wheels
- Expand community contacts

**Eligibility Specific**
- Has DDD/SDS
- Personal Care Attendant
- Supplemental
- Special Needs Trust

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# Ben’s Support Team

## CHARTING the LifeCourse

### Understanding My Health Care Team

<table>
<thead>
<tr>
<th>WHO</th>
<th>Relationship</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jane S.</td>
<td>Mom</td>
</tr>
<tr>
<td>Tom S.</td>
<td>Dad</td>
</tr>
<tr>
<td>Matt S.</td>
<td>Twin Brother</td>
</tr>
<tr>
<td>Zac S.</td>
<td>Older Brother</td>
</tr>
<tr>
<td>Ericka L.</td>
<td>Family Friend</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Formal Supports</th>
<th>(Who are paid people that might be with you and what their role is at the visit)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paid Staff (PCA, DSP):</td>
<td>Steve G.</td>
</tr>
<tr>
<td>Residential/Provider Agency Staff:</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Who Has Legal Authority</th>
<th>(Place a check next to who has legal decision-making authority and identify the person)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have Legal Decision-Making Authority for My Health Care</td>
<td>X</td>
</tr>
<tr>
<td>Power(s) of Attorney:</td>
<td>Tom S.</td>
</tr>
<tr>
<td>Guardian:</td>
<td>Sian S.</td>
</tr>
<tr>
<td>Conservator:</td>
<td></td>
</tr>
</tbody>
</table>

### Understanding My Support Needs

<table>
<thead>
<tr>
<th>Areas of Support for Medical Appointments/Events</th>
<th>What I Do/Need and Who Helps Me</th>
<th>Health Professional’s Role in Supporting Me</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understanding what the medical professionals are saying, recommending or instructing; helping me know my options, pros and cons</td>
<td>Who do I trust to help me understand and how do I communicate with them? I trust mom and dad and my brothers. I talk but sometimes other people have a hard time understanding me. My family understands me most of the time.</td>
<td>Writing down instructions, using photos or pictures to explain procedures or directions. I like for the doctor to talk to me, even if I need help understanding what he/she is saying. I like for them to treat me like anybody else. It helps to see photos, and write things down so whoever is with me doesn’t forget and can tell my mom and dad if they aren’t with me.</td>
</tr>
<tr>
<td>Communicating my current situation, my decisions/choices, and responding to or asking questions of medical professionals</td>
<td>Who helps me communicate with the medical professionals (doctor/nurse/care coordinator)? Mom and dad or my brothers are best. Ericka can help too. If I am with my staff, my mom has probably written everything down that he would need to tell the doctor for me.</td>
<td>Repeat my answers back to me; ask me to “teach back” instructions; ask me questions; Ask me questions, but give me plenty of time to process the question and answer. Don’t ask me another question before I have answered the first one. Sometimes you might need to reword a question to help me understand.</td>
</tr>
<tr>
<td>Following through with my medical choices, decisions, or following doctor/nurse/care coordinator’s instructions or treatment plan</td>
<td>Who helps with follow through reminders, set up medications, checking in with me? I know when to take my medications, but my mom or dad helps me get the right dose and with getting refills.</td>
<td>Send out reminders by mail or test; follow-up appointments; Send me and my mom or dad a reminder about my next appointment. Test or the mail works fine.</td>
</tr>
</tbody>
</table>

Developed by the UMKC Institute for Human Development, UCEDD. More tools and materials at lifecoursetools.com October 2018
Questions?
THANK YOU!!!

Jane St John
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