



Missouri's Journey to Supported Decision Making

July 23, 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



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



MO GUARDIANSHIP:
UNDERSTANDING YOUR
OPTIONS & ALTERNATIVES

A RESOURCE GUIDE
helping you understand how to:

- BALANCE SUPPORT & PROTECTION with autonomy and self-determination.
- IDENTIFY OPTIONS AND ALTERNATIVES
- ACCESS ALTERNATIVES TO GUARDIANSHIP as well as accessing Missouri courts to pursue your guardianship options.

- ◉ 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

Alternatives to

2nd Edition

IDENTIFYING ALTERNATIVES TO GUARDIANSHIP

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? _____

This checklist is a tool designed to be used *with* the purposes of the training program.

MO Guardianship: Understanding Your Options & 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 *not* exhaustive and are not intended to provide a final determination of what a person should (or should not) do in their unique circumstances.

	LEAST RESTRICTIVE: Individual Makes Own Decisions	Middle Individual Needs Support With Making Decisions	MOST RESTRICTIVE: Individual Has NO CHOICE to Make Decisions
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, etc. contacts)?			
MONEY MANAGEMENT			
Is the person able to manage their money (i.e. meet financial commitments, such as regular bills)?			
Is the person able to manage the monetary benefits he or she is supposed to receive?			
Is the person able to identify and resist 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?			
Can the person make and communicate decisions regarding medical treatment, including understanding the consequences of not accepting treatment?			
Does the person understand health consequences associated with high risk behaviors (substance abuse, smoking, high-risk sexual activities, etc.)?			
Can the person alert others and seek medical help for serious health problems?			

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MO-WINGS



Missouri's Working Interdisciplinary Network of Guardianship Stakeholders

[Home](#)[Process](#)[Next Steps](#)[Members](#)[Presentations](#)[Latest Master Draft](#)[Contact Us / Input](#)

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 (former chair of The Missouri Bar Probate and Trust Committee); and the late Reginald "Reg" Turnbull, a private practice attorney (former chair of the Missouri Bar Elder Law Committee.)

Members of MOWINGS have included representatives of persons with disabilities, parents, family members, lay guardians and conservators, service providers, AARP, 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 Protection 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.

[Calendar](#)

This website was funded through a grant from the Missouri Developmental Disabilities Council under provisions of P.L. 106-402, the Developmental Disabilities Assistance and Bill of Rights Act 2000

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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 Sparks 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)
- ⦿ 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
- ⦿ Clear and convincing evidence of incapacity, and **evidence that needs cannot be met by a less restrictive alternative**
- ⦿ Respondents **rights** at hearings



Summary of Statute Revisions to Guardianship Code

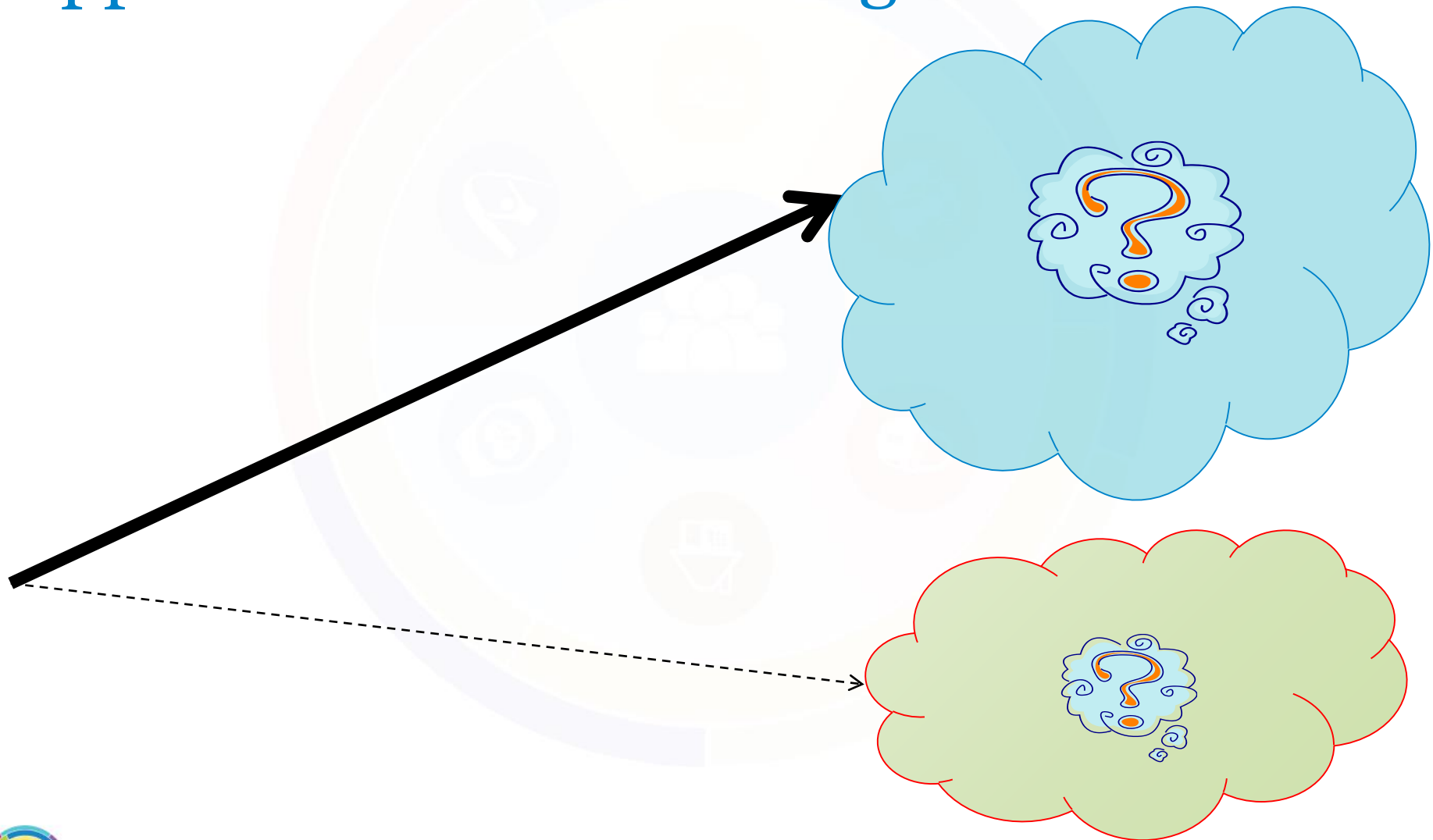
- ⦿ Court must now consider if respondent's needs can be met by a **less restrictive alternative** before appointing a guardian (specifically states **SUPPORTED DECISION MAKING AGREEMENTS**)
- ⦿ Required specific findings (including retention of rights to vote, drive or marry; placement or management of other essential needs)
- ⦿ **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**



So, What's NEXT?



Missouri's Vision & Trajectory for Supported Decision Making



Supported Decision Making Symposium

September 12, 2018



Missouri & Protection
Advocacy Services

UMKC Institute for
Human Development
A University Center for Excellence in Developmental Disabilities



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

FEATURING
Jonathan Martinis



and
Morgan
Whitlatch

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



Launch of Missouri Consortium on SDM

March 31st, 2019



MISSOURI CONSORTIUM ON SUPPORTED DECISION MAKING

REGISTER TO ATTEND:

<https://mo-sdm-consortium1.eventbrite.com>

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.**

Riechmann Indoor Pavilion



located in Stephens Lake Park

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**





Supported Decision Making Tools and Resources



IDENTIFYING ALTERNATIVES TO GUARDIANSHIP

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? _____

This checklist is a tool designed to be used *only* for the purposes of the training program.

MO Guardianship: Understanding Your Options & 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 *not* exhaustive and are *not* intended to provide a final 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)?

MONEY MANAGEMENT

Is the person able to manage their money (i.e. meet financial commitments, such as regular bills)?

Is the person able to manage the monetary benefits he or she is supposed to receive?

Is the person able to identify and resist 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 medicines as directed?

Does 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?

Does the person understand health consequences associated with high risk behaviors (substance abuse, overeating, high-risk sexual activities, etc.)?

Can the person alert others and seek medical help for serious health problems?

LEAST RESTRICTIVE:	→ → →	MOST RESTRICTIVE:
Individual Makes Own Decisions	Individual Needs Support With Making Decisions	Individual has NO RIGHTS to Make Decisions
"YES" If the answer is "YES," place a ✓ in the box.	"NO" If there is an ALTERNATIVE that meets this need, list it below.	"NO" Place a ✓ in the box and consider whether you need to address the need through one of the GUARDIANSHIP OPTIONS.
If the answer is "NO," go to next column. →	If NO Alternative meets this need, go to next column. →	

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IDENTIFYING ALTERNATIVES TO GUARDIANSHIP

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

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? _____

Step 1: Decide for each question if the answer is yes or no. If yes, put a checkmark in the GREEN column – this means the person is good to go. If NO, put a mark in the yellow column.

Step 2: When you have completed all the questions, explore alternatives to guardianship to meet the supported decision making need for all questions marked in the yellow column.

Step 3: ONLY if NO alternative can be identified, then limited guardianship might be considered for those specific areas of need.



Can person decide or direct this activity independently most of the time?



Can person decide or direct this activity with assistance most of the time?



Does the person require substituted decision making support?



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)?

Is the person able to manage their money (i.e. meet financial commitments, such as regular bills)?

Is the person able to manage the monetary benefits he or she is supposed to receive?

Is the person able to identify and resist financial exploitation?



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?

Does 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?

Does the person understand health consequences associated with high risk behaviors (substance abuse, overeating, high-risk sexual activities, etc.)?


Can the person alert others and seek medical help for serious health problems?

Is the person able to decide and direct what kinds of support they need or want and select who provides those supports?

UMKC Institute for Human Development, UCEDD

moguardianship.com

Exploring Supported Decision Making

CHARTING the LifeCourse 

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: _____

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?			
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?			

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CHARTING the LifeCourse 

Tool for 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 can decide with no extra support	 I need support with my decision	 I need someone 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 (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 (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, 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' home)?			
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 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 (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		
My Personal Support Team <i>(Identify your personal supporters and their relationship to you)</i>	Formal Supports <i>(Who are paid people that might be with you and what their role is at the visit)</i>	Who Has Legal Authority <i>(Place a check next to who has legal decision-making authority and identify the person)</i>
WHO Relationship <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>	Paid Staff (PCA, DSP): <hr/> <hr/> Residential/Provider Agency Staff: <hr/> <hr/> Other: <hr/> <hr/>	<input type="checkbox"/> I have Legal Decision-Making Authority for My Health Care <input type="checkbox"/> Power(s) of Attorney: <hr/> <hr/> <input type="checkbox"/> Guardian: <hr/> Circle one: Plenary(full) OR Limited <input type="checkbox"/> Conservator: <hr/>

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

Tool for Understanding the Decision Making Support Needs and Team



CHARTING the LifeCourse



TODAY'S HEALTH CARE VISIT

COMPLETE BEFORE THE VISIT

My Name: _____

Today's Date: _____

Who is with me today? _____

Current list of my medications, pills, and vitamins
(attach it for the doctor or nurse)

Do I have a plan or card that pays for my medicine?

Yes No (list) _____

Did I recently go see any other doctor or dentist?

YES (who?) _____ NO

What was the reason?

Why am I at the doctor's or clinic today?

(Things like illness, check-up, follow-up from previous visit,
need forms filled out, need medication change or refill, etc.)

Questions I want to ask today

Answers to my questions

MY TAKE-AWAY INFORMATION

Were there any **Medication or Diet Changes**?

YES or NO If YES:

Medication Name: _____

I am to take this _____ times per day, at _____

I am to stay on this for _____ days (or specify _____)

Why do I need to take this?

Medication Name: _____

I am to take this _____ times per day, at _____

I am to stay on this for _____ days (or specify _____)

Why do I need to take this?

Are there medications I don't need to take anymore, or
anything else I should know?

Information about today's treatment plan,
recommendations, and/or follow-up

(for ME, my family, caregivers, or other supporters)

medical professional signature

date

staff or provider signature

date

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?



The Right to Make Choices



Introduction to Supported Decision-Making



Do I HAVE to get Guardianship?

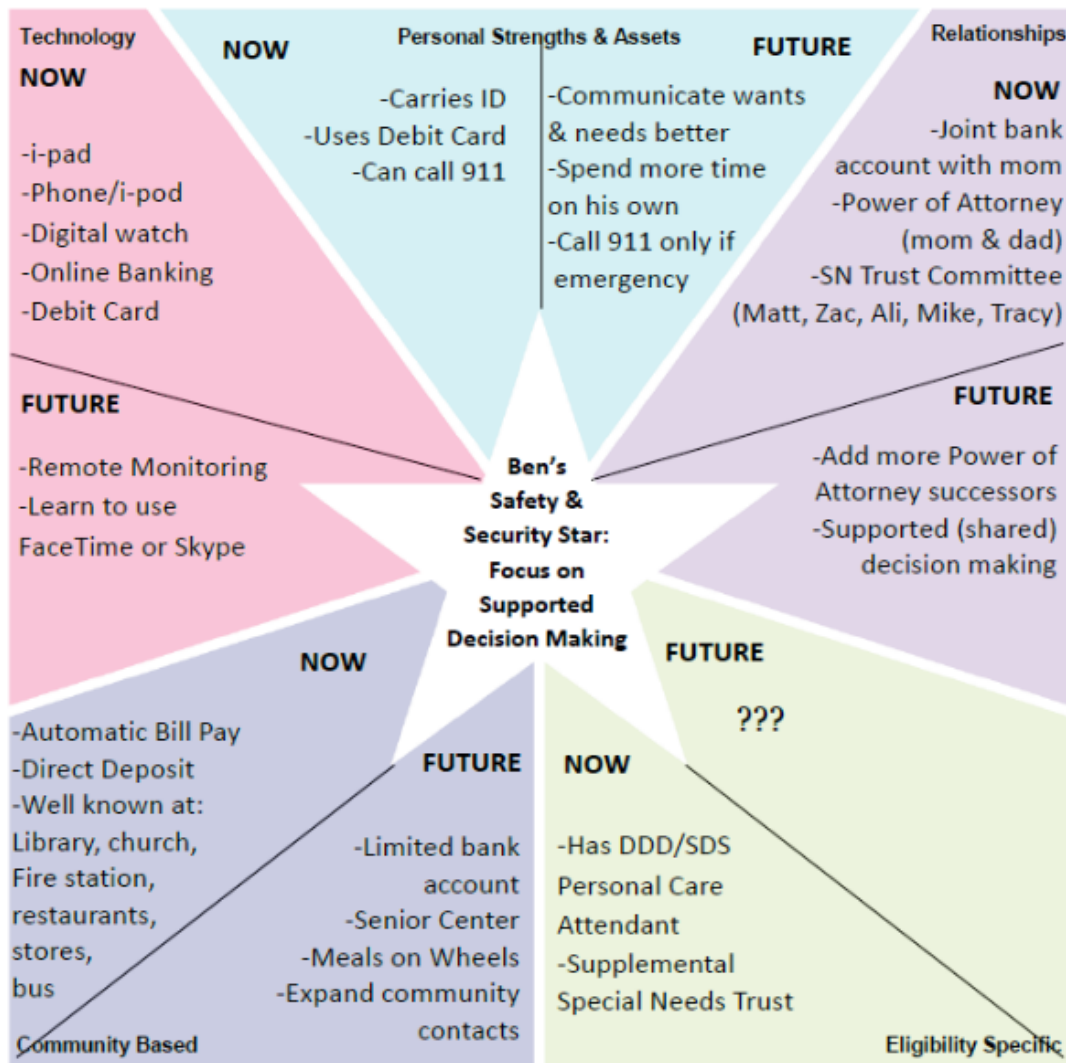
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Supported Decision-Making Series



Ben's SDM Supports





UNDERSTANDING MY HEALTH CARE TEAM

My Personal Support Team <i>(Identify your personal supporters and their relationship to you)</i>		Formal Supports <i>(Who are paid people that might be with you and what their role is at the visit)</i>	Who Has Legal Authority <i>(Place a check next to who has legal decision-making authority and identify the person)</i>
WHO	Relationship		
Jane S.	Mom	Paid Staff (PCA, DSP): Steve G.	<input checked="" type="checkbox"/> I have Legal Decision-Making Authority for My Health Care
Tom S.	Dad		<input checked="" type="checkbox"/> Power(s) of Attorney: Tom S.
Matt S.	Twin Brother	Residential/Provider Agency Staff:	Jane S.
Zac S.	Older Brother		Guardian: Circle one: Plenary(full) OR Limited
Ericka L.	Family Friend	Other: _____	Conservator: _____

UNDERSTANDING MY SUPPORT NEEDS

Areas of Support for Medical Appointments/Events	What I Do/Need and Who Helps Me	Health Professional's Role In Supporting Me
Understanding what the medical professionals are saying, suggesting, recommending or instructing; helping me know my options, pros and cons	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.	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.
Communicating my current situation, my decisions/choices, and responding to or asking questions of medical professionals	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.	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.
Following through with my medical choices, decisions, or following doctor/nurse/care coordinator's instructions or treatment plan	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.	Send out reminders by mail or text; follow-up appointments; Send me and my mom or dad a reminder about my next appointment. Text or the mail works fine.

Ben's Support Team



Questions?





THANK YOU!!!

Jane St John
stjohnj@umkc.edu

