

Supporting Self-Determination and Employment through Supported Decision-Making



LEADING CHANGE TOGETHER

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Supported Decision-Making & Employment: One Family's Experience

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University Center for Excellence in
Developmental Disabilities

Georgetown University Center for Child and
Human Development



Self Determination????? What is it????

- It's about making things happen in your own life!
- It involves supports, opportunity for making choices, making decisions and more!



What Do We Mean by Self Determination?

Self determination is

- believing you can control your own destiny
- setting goals for yourself
- being in charge
- making your own choices,
- learning to effectively solve problems, and
- taking control and responsibility for one's life.

What Do We Mean by Self Determination?

Practicing self-determination also means
one experiences the consequences of
making choices

Adapted from Pacer Center

[http://www.pacer.org/tatra/resources/self.a
sp](http://www.pacer.org/tatra/resources/self.asp)

What is Supported Decision-Making????

- Supported Decision-Making helps a person with a disability (and others, too) make and communicate decisions about their life!
- It's about relationships, communicating and agreements between a person and her or his supporter!

CHARTING the LifeCourse

Life Trajectory Worksheet – Exploring Nicci



VISION for WHAT I WANT

List what you want your “GOOD LIFE” to look like

- Respect, acceptance and inclusion in my community
- Friends and family to love
- A boyfriend
- Meaningful employment
- Interesting and fun things to do
- Good health and free from pain
- Earn my GED

WHAT I DON'T WANT

List the things you don't want or what is NOT a “good life”

- Days with nowhere to go
- Days spent watching TV
- A boring life without friends and family
- People making my decisions
- People speaking for me, unless I ask
- People treating me like I'm invisible or stupid

Mostly shred from home and still shred orders for my church; looking for new location

Mention to my doctor that I lost my space in the church. My doctor gave me space in her office (but it's very small and transportation to and from the office is a problem)

Ask DORS again for assistance and receive funding for (limited) tutoring to improve my reading skills

Church finds paying tenant for my space, so I move my business back home

Shred papers in my church space 2-3x week, and “hired” another person with a disability to help (but it didn't work out)

Ask to use space in my church – a 5- month long process, but after much persistence I was given a secure space, with the understanding that I'd have to move if and when the space was rented out

Ask DORS for funding for shredding business, but told I need a business location

Volunteer with Pyramid Atlantic Store stamping merchandise bags and shredding papers

Always ask new and old friends and customers whether they have any papers I can shred - not shy at all

Decide to start a paper shredding business, and works from home. Friends and family developed flyers, researched business aspects, developed a business plan

Tried work experiences in high school, but none fit

Supported Decision-Making: What, Why, How

Morgan K. Whitlatch

Quality Trust for Individuals with Disabilities

Supported Decision-Making: What?

- Supports that help people make their own decisions by using others they trust:
 - To help understand issues/choices
 - Ask questions, receive explanations
 - Communicate their own decisions

(See, e.g., Blanck & Martinis, 2015; Dinerstein, 2012; Salzman 2011).

Supported Decision-Making: Why?

- Self-Determination = Life Control
 - People’s ability and opportunity to be “causal agents . . . Actors in their lives instead of being acted upon”

(Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000, p. 440)

It Makes Sense!

- Studies have shown that people with greater self-determination are:
 - More independent
 - More integrated into their communities
 - Healthier
 - Better to able and recognize abuse

More Evidence

- Students with disabilities who have self-determination skills are more likely to successfully make the transition to adulthood, including improved education, employment, and independent living outcomes

(See Shogren, Wehmeyer, Palmer, Rifenburg & Little 2015; Powers, Geenen, Pommier-Satya, Turner, Dalton, et al, 2012; Wehmeyer & Schwartz, 1997)

More Evidence

- 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)

And More Evidence

- When denied self-determination, people can:
 - “[F]eel helpless, hopeless, and self-critical” (Deci, 1975, p. 208)
 - Experience low self-esteem and passivity, decreasing their ability to function (Winick 1995, p. 21; Wright, 2010, p. 354)

Supported Decision-Making: How?

- There is no “one size fits all” method
 - SDM looks different for different people
- It is a paradigm, not a process or program
 - Ask: What will it take?
 - Work with the person to identify what help is needed and wanted and how to provide it.

Common Considerations

- All forms of SDM recognize:
 - Autonomy, presumption of capacity, and right to make decisions on an equal basis with others.
 - Take part in a decision-making approach that does not remove rights.
 - People will often need assistance

(See Dinerstein, 2012)

Rethink “Capacity”

- “Capacity” is not:
 - “all or nothing” or
 - based solely on IQ or diagnosis.
- People may have “capacity” to:
 - Make some decisions and not others
 - Made decisions at some times and not others
 - Make decisions if they get help understanding

Rethink

“Human Decision-Making”

- Typical decision-making is flawed
- No standard way to measure “goodness”
- Most life decisions are personal, based on culture and values.
- Brain and decision-making science are deepening understanding of ways to help.

Looking Nationally...

- U.S. Administration for Community Living
- National Resource Center for SDM (2014 to present)
 - www.SupportedDecisionMaking.org
- National Guardianship Association (2016)
- Social Security Advisory Board (2016)
- American Association on Intellectual & Developmental Disabilities & The Arc of the U.S. (2016)

More References to SDM

- American Bar Association (2016 & 2017)
- Uniform Guardianship, Conservatorship, & Other Protective Arrangements Act (2017)
- U.S. Department of Education, Office of Special Education and Rehabilitative Services, “Transition Guide to Post-Secondary Education & Employment for Students & Youth with Disabilities” (2017)

More References to SDM

- National Council on Disability Reports
 - “Beyond Guardianship” (2018)
 - “Turning Rights Into Reality: How Guardianship and Alternatives Impacts People with Intellectual Disabilities” (2019)
 - “Tosha’s Story”: Impact on Employment
- U.S. Senate Special Committee on Aging, “Ensuring Trust” Report (2018)

U.S. State Trends in SDM

- NRC-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: FL, IN, KY, MA, ME, MN, NV, NY, PA, VA, VT

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 - Examples: FL, IN, KY, MA, ME, MN, NV, NY, PA, VA, VT

U.S. State Trends in SDM

- At least 30 states and DC have introduced SDM legislation/resolutions
 - AK, AR, CA, CT, DC, DE, IL, IN, KS, KY, LA, ME, MD, MA, MN, MO, MT, NV, NM, NY, NC, ND, OH, OR, RI, TN, TX, UT, VA, WA, WI
 - As of 9/9/2019

U.S. State Trends in SDM

- Of these, 17 have enacted legislation or resolutions referring to SDM.
 - AK, DC, DE, IN, KS, LA, ME, MD, MO, NV, ND, OH, RI, TX, VA, WA, WI
 - SDM Agreements, UGCOPAA or Less-Restrictive Alternative, Education, Organ Transplantation, SDM Studies, and more!

National Community of Practice
and Charting the LifeCourse
Framework:
Supported Decision Making and
Employment Outcomes

Jane St. John



GOAL of the CoP

To build capacity, *through a community of practice*, across and within States to create policies, practices and systems to better assist and support families that include a member with an intellectual and developmental disability across the lifespan.

National Community of Practice



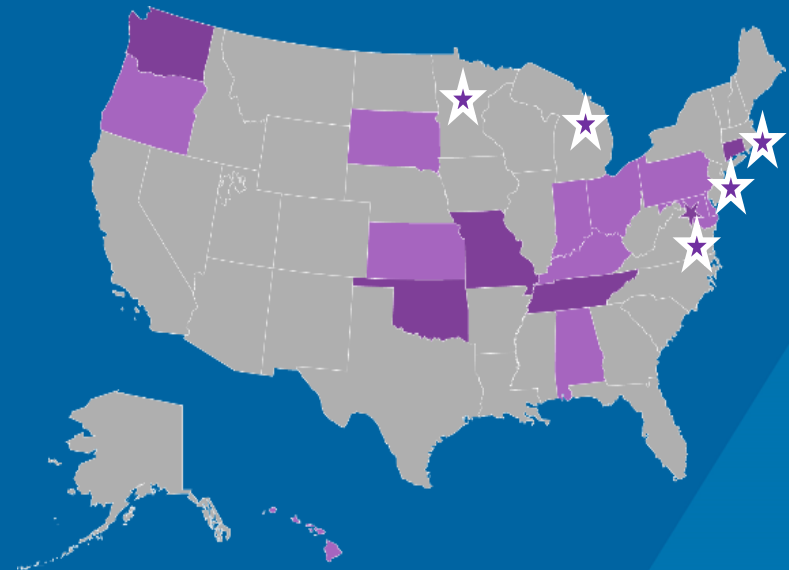
SUPPORTING FAMILIES
of individuals with intellectual & developmental disabilities
THE NATIONAL COMMUNITY OF PRACTICE FUNDED BY THE ADMINISTRATION ON INTELLECTUAL & DEVELOPMENTAL DISABILITIES

Charting the LifeCourse Framework



Developed by and for people with disabilities and their families

National Community of Practice on Supporting Families



Hosted by NASDDDS & UMKC-IHD, UCEDD



Employment – Lens of the CoP

Encourage Policies, Practices, and Strategies in CoP States to:

- 1) Encourage and support the role of family members in setting expectations and helping their family members explore employment
- 2) Provide supports including individual skill development for job seekers, access to potential related supports, and partnerships between states and families to break down down potential barriers to employment.

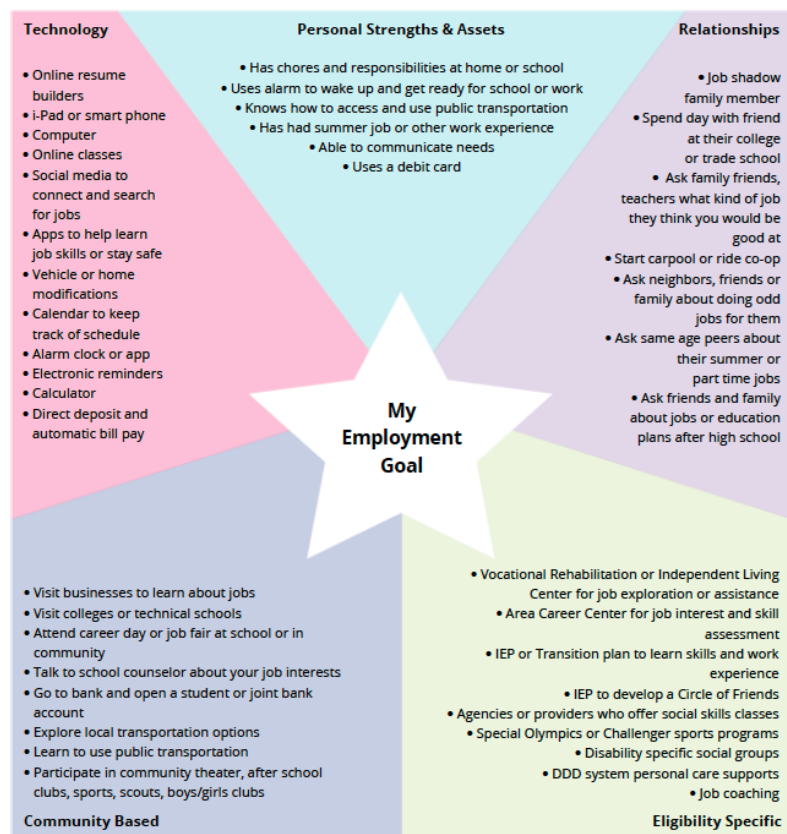
Lens of LifeCourse: Employment and Supported Decision Making

CHARTING the LifeCourse



Integrated Supports: Employment

People need supports to lead good lives. Using a combination of lots of different kinds of support helps to plot a trajectory toward an inclusive, quality, community life. This tool will help families and individuals think about how to work in partnership to support their vision for employment.



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

DECEMBER 2015

CHARTING the LifeCourse



Integrated Supports: 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.



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February 2019

Missouri's Journey to Supported Decision-Making

Mo Guardianship: Understanding Options and Alternatives 2009/2013

- Partnership: UMKC-IHD, UCEDD; MO Protection & Advocacy; MO Developmental Disabilities Council; and People First of Missouri
- Promoted making informed decisions about guardianship options & alternatives with emphasis on supported decision making

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.

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: _____
 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 of 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 the action independently most of the time?	Can person decide or direct the action with assistance most of the time?	Does the person require supported decision-making?
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 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 (alcohol or drug use, 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 mo-guardianship.com

Summary of Statute Revisions to Guardianship Code

- Missouri's Working Interdisciplinary Network of Guardianship Stakeholders (MO-WINGS) met for 6 years working on statutory reform
- Changes to Missouri's Guardianship and Conservatorship Statute Chapter 475, RSMO (Revised Statutes of Missouri)
- Senate Bill 806, August 28, 2018

Summary of Statute Revisions to Guardianship Code

- Appointment Priority (Court to appoint suitable relative over unrelated 3rd party)
- Co-Guardians
- Respondents **rights** at hearings

Summary of Statute Revisions to Guardianship Code

- 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**

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)

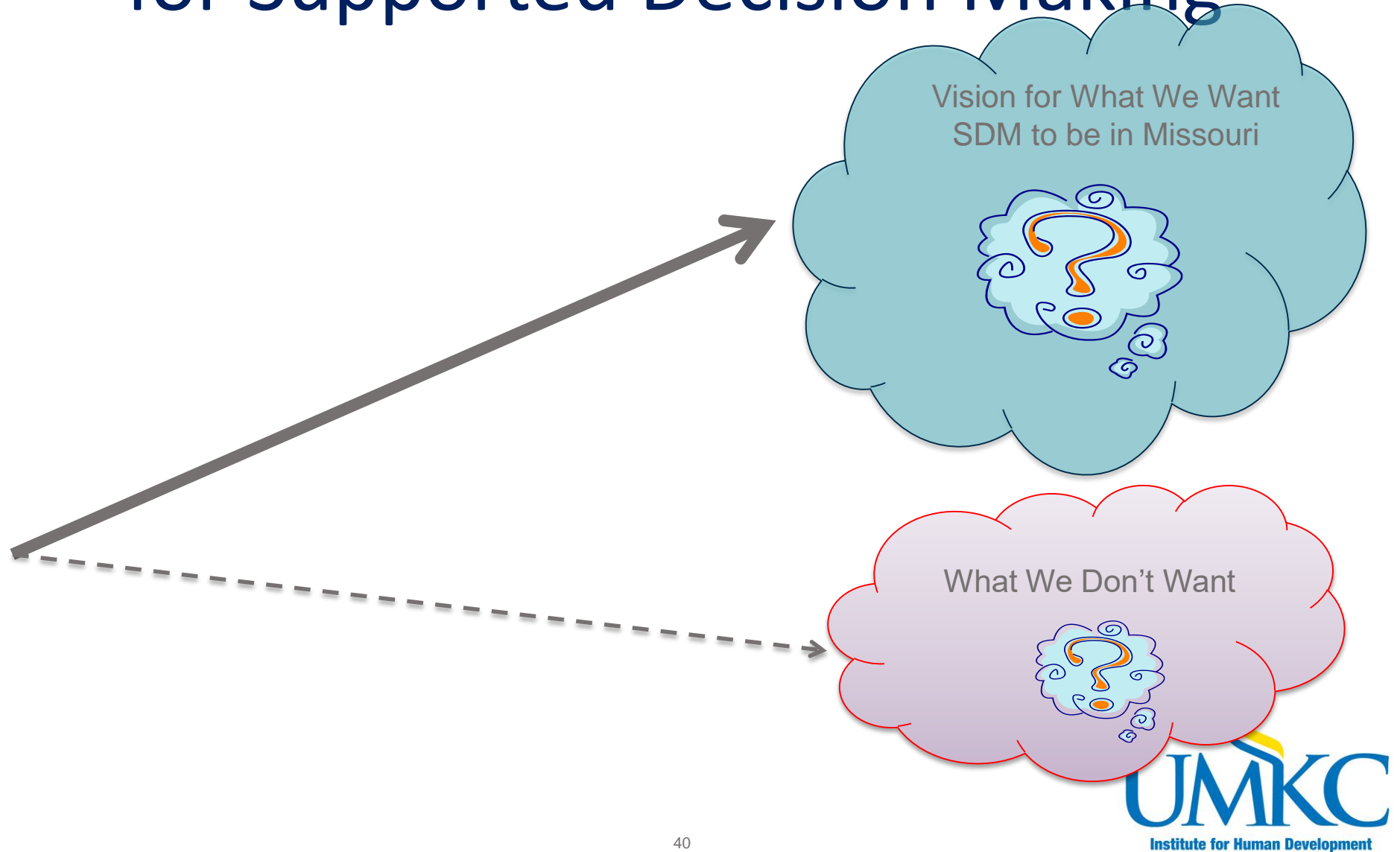
Summary of Statute Revisions to Guardianship Code

- **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**

Changing the Law is just
the beginning...

So, What's NEXT?

Missouri's Vision & Trajectory for Supported Decision Making



Supported Decision Making Symposium

– September 2018

AGREED UPON GUIDING PRINCIPLES

1. Everyone has equal right to make their own decisions, regardless of diagnosis or functional challenges.
2. Respect opinions & deeply held beliefs that led parents and advocates to choose different options for decision-making support
3. Promote practices that provide individualized decision-making assistance that imposes the absolute minimum restriction of rights

Launch of Missouri Consortium on SDM



March 31,
2019

Recommendations from SDM Symposium

Review & expand existing SDM
projects & resources

Develop new projects & resources
to advance SDM

Identify, acknowledge, & overcome
challenges and obstacles to
implementing SDM in Missouri

Consortium members identified
and prioritized strategies and tools
to implement SDM in Missouri

Launch of Missouri Consortium on SDM



5 work groups to continue progress between meetings:

- Training & Education
- Tools & Resources
- Research & Data
- Outreach & Awareness
- State/Local Policies and Practices

Pilot:

Charting the LifeCourse Health Care Preferences and Supported Decision Making for People with IDD



CtLC Health Care Preferences and Supported Decision Making

- Enhance partnership between medical professionals, adults with IDD, family members, and disability providers that supports informed choice and SDM practices on health care decisions
 - Training & coaching on SDM
 - Develop and disseminate Charting the LifeCourse Healthcare Training and Coaching Toolkit

CtLC Health Care Preferences and Supported Decision Making

- **Self-Advocates** - increased knowledge, skills and confidence for **making decisions in healthcare settings.**
- **Family members and disability staff** - increased skills and knowledge of the Supported Decision Making (**SDM**) process
- **Medical Professionals** demonstrate increased knowledge of IDD & increased skills and confidence to partner in the SDM process leading to **informed consent**

Supported Decision-Making: Tools and Resources

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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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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More Supported Decision Making Tools

CHARTING the LifeCourse 

UNDERSTANDING MY HEALTH CARE TEAM


My Personal Support Team <i>(Identify your personal supporters and their relationship to you)</i>	Formal Supporters <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: _____	Paid Staff (PCA, DSP): _____ Residential/Provider Agency Staff: _____ Other: _____	_____ I have Legal Decision-Making Authority for My Health Care _____ Power(s) of Attorney: _____ Guardian: Circle one: Plenary(full) OR Limited _____ 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?	Writing down instructions, using photos or pictures to _____
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 "teach me" _____
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 appointment _____

Developed by the UMKC Institute for Human Development, UCEDD. More tools and materials at lifecoursetools.com

The Right to Make Choices



Introduction to Supported Decision-Making



Life Trajectory Worksheet: Supported Decision Making

WHAT DO I NEED TO MAKE GOOD CHOICES AND DECISIONS?

What helps me UNDERSTAND the issues and my options?

What helped in the past?	What do I need now?
--------------------------	---------------------

What helps me COMMUNICATE my preferences, choices, and decisions?


What helped in the past?	What do I need now?
--------------------------	---------------------

What helps me FOLLOW THROUGH on my choices and decisions?

What helped in the past?	What do I need now?
--------------------------	---------------------


VISION for What I Want


What decisions and choices do I want to make myself or with help from my supporters?

My 

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 

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-ups, follow-up from previous visit, need for a (fill 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 _____

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

Ben

CHARTING the LifeCourse



Tool for Exploring Decision Making Supports

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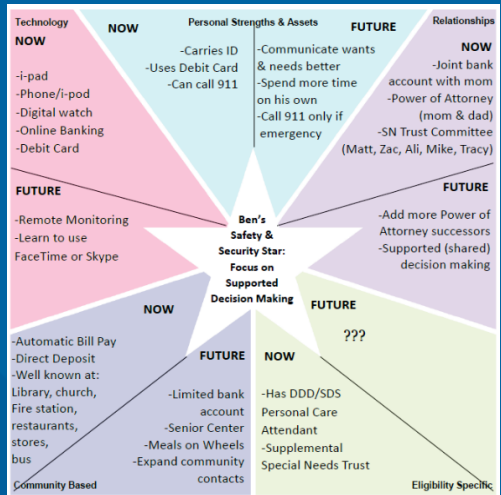
Name of Individual: Ben
 Name of person completing this form: Ben with help from Mom [lane]
 Relationship to individual (circle one): Self Family Friend Guardian Other:
 How long have you known the individual? 28 years

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	I can decide with no extra support	I need support with my decision	I need someone to decide for me
Can I decide if or where I want to work?		X	
Can I look for and find a job (read ads, apply, use personal contacts)?		X	
Do I plan what my day will look like?		X	
Do I decide if I want to learn something new and how to best go about that?		X	
Can I make big decisions about money? (open bank account, make big purchases)		X	
Do I make everyday purchases? (food, personal items, recreation)		X	
Do I pay my bills on time (rent, cell, electric, internet)?		X	
Do I keep a budget so I know how much money I have to spend?		X	
Am I able to manage the eligibility benefits I receive?			X
Do I make sure no one is taking my money or using it for themselves?			X
HEALTHY LIVING			
Do I choose when to go to the doctor or dentist?		X	
Do I decide/direct what doctors, medical/health clinics, hospitals, specialists or other health care providers I use?		X	
Can I make healthy/medical choices for my day-to-day well-being? (check-ups, routine screening, working out, vitamins)		X	
Can I make medical choices in serious situations? (surgery, big injury)			X
Can I make medical choices in an emergency?		X	
Can I take medications as directed or follow a prescribed diet?		X	
Do I know the reasons why I take my medication?		X	
Do I understand the consequences if I refuse medical treatment?		X	
Can I alert others and seek medical help for serious health problems?		X	
Do I make choices about birth control or pregnancy?	n/a		
Do I make choices about drugs or alcohol?	X		
Do I understand health consequences associated with choosing high risk behaviors (substance abuse, overeating, high-risk sexual activities, etc.)?		X	
Do I decide where, when, and what to eat?	X		
Do I understand the need for personal hygiene and dental care?	X		

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Ben's Support Team

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>												
<table border="1"> <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>	WHO	Relationship	Jane S.	Mom	Tom S.	Dad	Matt S.	Twin Brother	Zac S.	Older Brother	Ericka L.	Family Friend	Paid Staff (PCA, DSP): Steve G. <hr/> Residential/Provider Agency Staff: <hr/> Other: _____ <hr/>	<input checked="" type="checkbox"/> I have Legal Decision-Making Authority for My Health Care <input checked="" type="checkbox"/> Power(s) of Attorney: Tom S Jane S <hr/> Guardian: _____ Circle one: Plenary(full) OR Limited <hr/> Conservator: _____
WHO	Relationship													
Jane S.	Mom													
Tom S.	Dad													
Matt S.	Twin Brother													
Zac S.	Older Brother													
Ericka L.	Family Friend													

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 answer 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.



District of Columbia



Landscape for Systems Change: DC's History

- Longstanding class action litigation
 - Need to embed values throughout system to reach compliance
 - Envisioning and starting to build a system for all, beyond compliance
- Self-Advocates demanding better outcomes around employment
- Families seeking more control, less guardianship and state commitment

People and Families Set Priorities for Systems Change

- Self-Determination and Supported Decision-Making
- Person and Family Centered Supports
- Employment
- Peer Supports
- Coordinated Lifespan Supports
- Comprehensive Supports for People with I/DD

Braiding Resources

- Supporting Families Community of Practice
- Employment First (EFSLMP + Vision Quest)
- No Wrong Door for LTSS
- Transition – Partners in Employment
- Community of Practice on SDM
- Cultural and Linguistic Competency CoP
- + DC investment in Person-Centered Thinking

Building Partnerships:

Change Happens at the Speed of Trust

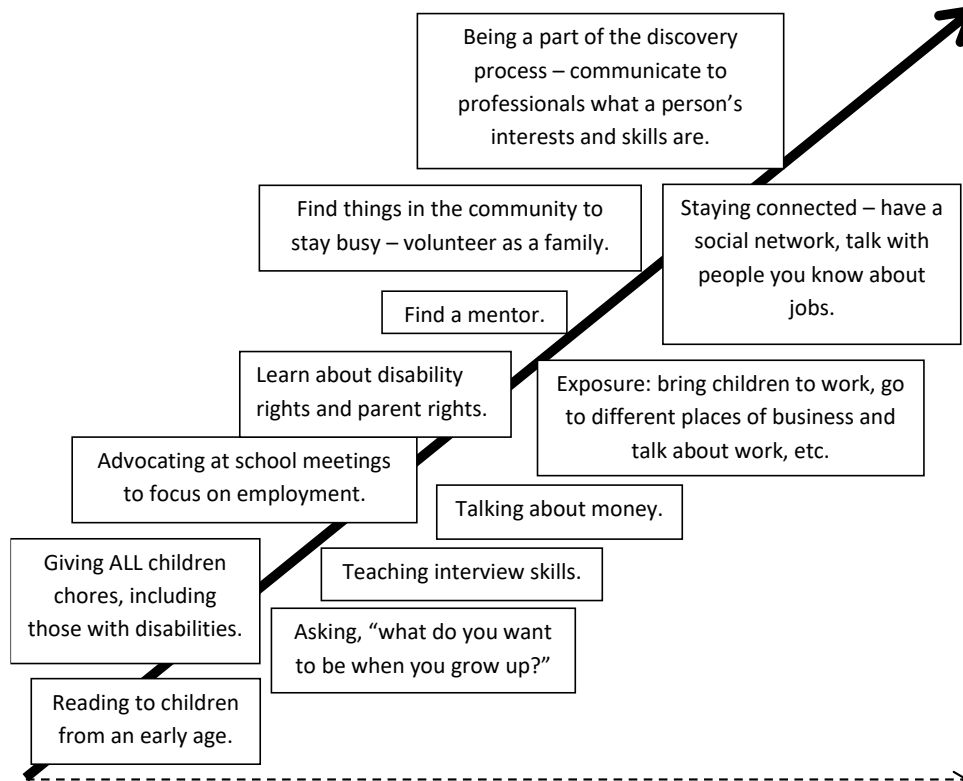
- Developmental Disabilities Administration
- Developmental Disabilities Council
- University Center for Excellence in Developmental Disabilities
- Protection & Advocacy Organization
- Self-Advocacy Group
- Advocacy Organizations
- Parent Training & Information Center
- And more

Talking to Families About Employment

Life Trajectory Worksheet: Family Focus on Employment

Families discussed, what works to support employment?

Believe, Encourage, Be Creative



VISION for the Life I WANT

- Employment – a good job that creates meaning and economic self sufficiency
- Independence – doing as many things independently as possible and as desired
- Self-determination – making one's own decisions
- To have a mentor- someone to look up to who understands each person's experience.
- To contribute to other family members

What I DON'T Want

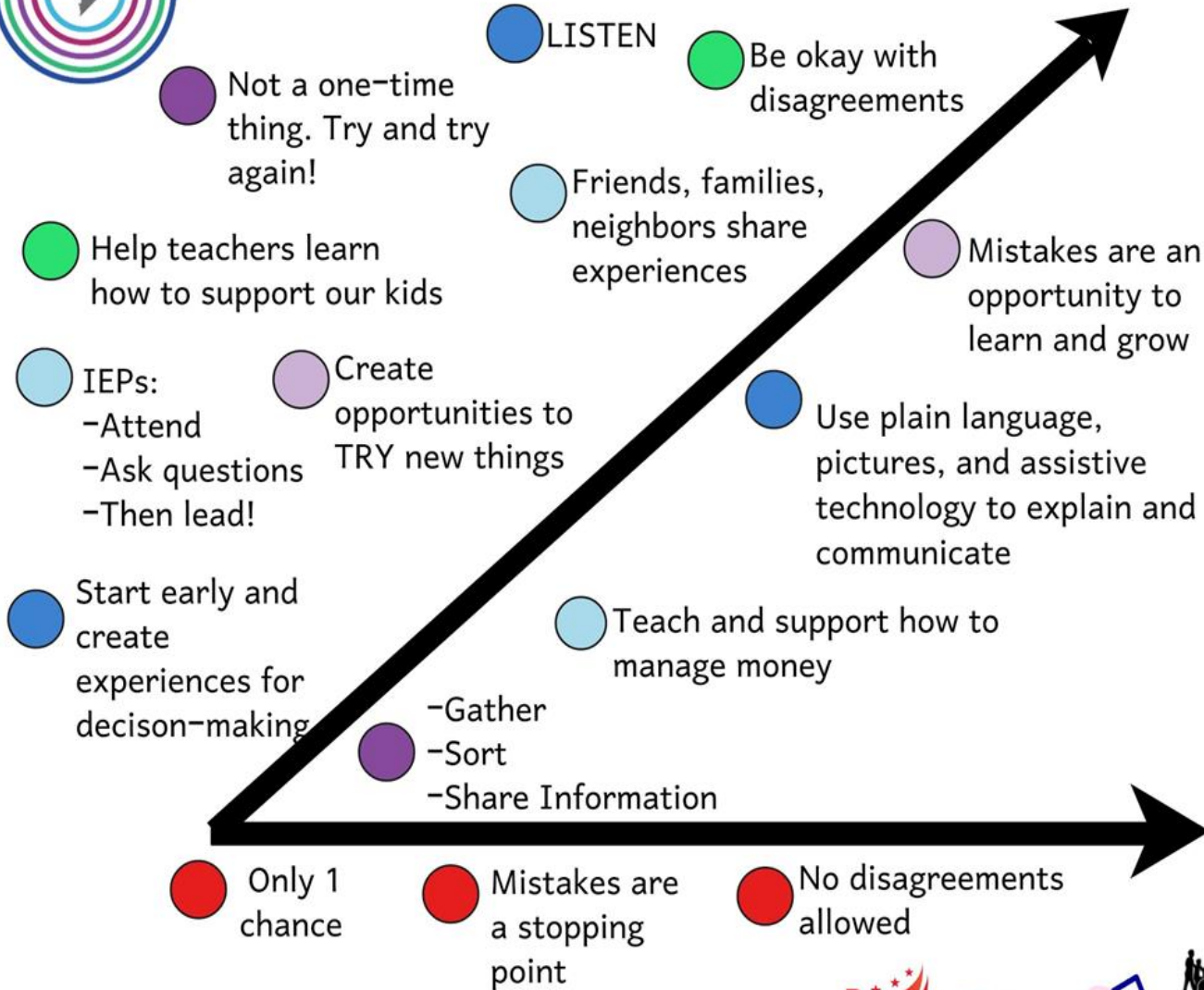
- To be discouraged by professionals
- To give Up Hope
- Boredom
- To not have a social network of friends or employment contacts
- Negativity and low expectations



This tool was adapted by the DC Department on Disability Services, from tools developed by University of Missouri-Kansas City Institute for Human Development, University Center for Excellence in Developmental Disabilities (2015). (Last revised 01/17)



DC'S SF CoP Ideas about SDM



What We Want

- *Feel POWERFUL
- *Be my own boss
- *Be in charge of my own life
- *Have control and self-determination
- *Have a good job and make money
- *Have friends and socialize
- *Go on dates
- *Live independently

What We Don't Want

- *Lonely - only friends are staff
- *No control- people make decisions for me
- *No job/no money
- *Not getting needed supports



Characteristics of a Good Supporter



Findings from DC Family Support Council
World Cafes on Supported Decision-Making

Discussion



Closing Thoughts

“It’s a Good Thing... I tell my supporter my decision, and my plan. Then I follow up later just to let them know what happened.”

- Ketrina Hazell, Self-Advocate, Supported Decision-Making New York

Closing Thoughts

“It’s simply something the rest of us take for granted.”

- Robert Dinerstein, Professor, American University, Washington College of Law

Closing Thoughts

“Take away the ‘disability lens’ – it just looks like life.”

- Judge Kristen Booth Glen, Dean Emerita,
CUNY School of Law

Appendix

Presenter Bios and Contact Information

Joan Christopher



- Research Instructor and Director of Community Services, UCEDD, Georgetown University.
- Parent of an adult daughter with disabilities and supports her in her business.

Contact Joan

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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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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

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Institute for Human Development

Charting the LifeCourse

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Kara Nicole Jones (“Nicci”)



Kara Nicole Jones (“Nicci”)

Kara is a young woman who lives in Silver Spring, MD with her family. She’s an active member of Project Action!, People On The Go of Maryland and the Women’s Knowledge Group. She is also a member of the Stewardship Committee at Grace Episcopal Church. Kara has her own paper shredding business and is very active in her community. She has testified in public forums and enjoys making decisions about her life.

Nikki

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

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Acronyms

Acronyms

- CoP: Community of Practice
- CtLC: Charting the LifeCourse
- EFSLMP: Employment First State Leadership Mentoring Program
- IDD: Intellectual and Developmental Disability
- IQ: Intelligence Quotient
- LTSS: Long Term Services and Supports

Acronyms

- MO-WINGS: Missouri's Working Interdisciplinary Network of Guardianship Stakeholders
- RSMO: Revised Statutes of Missouri
- SDM: Supported Decision-Making
- SF CoP: Supporting Families Community of Practice

Acronyms

- UCEDD: University Center for Excellence in Developmental Disabilities
- UGCOPAA: Uniform Guardianship, Conservatorship, and other Protective Arrangements Act
- UMKC-IHD: University of Missouri Kansas City – Institute for Human Development

Resources Attached as Handouts

Thank You!