My Choice Kentucky: Grassroots efforts to expand supported decision-making in Kentucky

Laura N. Butler, MRC
Human Development Institute
University of Kentucky

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Agenda

- Overview of project history
- Partners, Collaborators, and Funders
- Useful Tools and Resources
- SDM at Work in Kentucky

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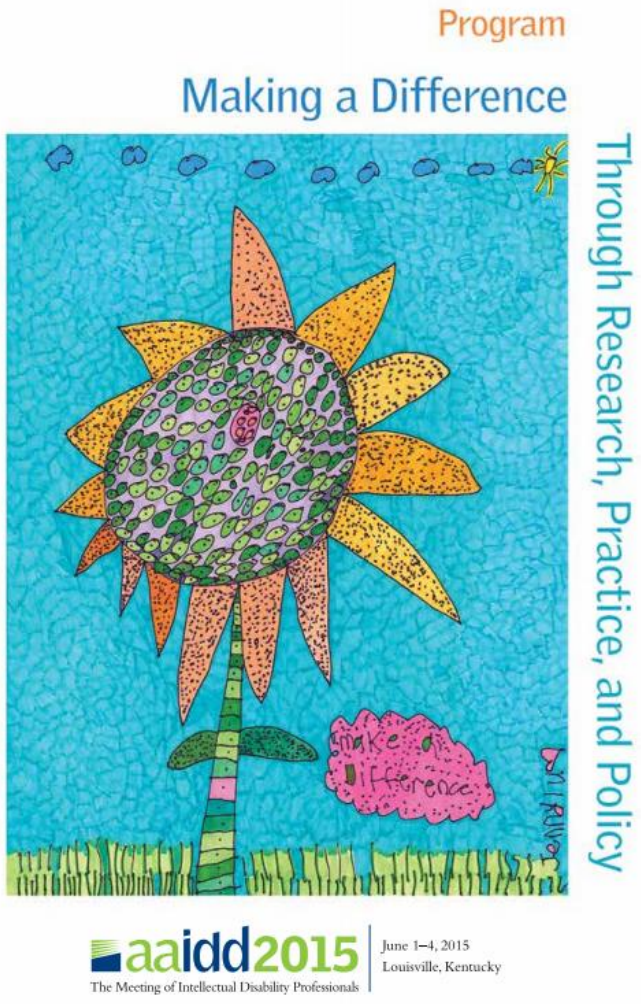
How We Got Here



ADVOCACY AND DECISION MAKING

Moderator:
Holly Riddle, JD, Chair, AAIDD Legal Process & Advocacy Division

National Resource Center for Supported Decision-Making: Preliminary Developments and Outcomes
Tina Campanella, MA, Quality Trust for Individuals with Disabilities
Jonathan Martinis, JD, Quality Trust for Individuals with Disabilities
Michael Wehmeyer, PhD, FAAIDD, University of Kansas

Voice & Advocacy—Complexities of the Guardian's Role
Alya Reeve, MD, University of New Mexico
Eula Michaels, University of New Mexico

System Change to Promote Rights: National Core Indicators Data and a Supported Decision Making Initiative
Elizabeth Pell, MSW, Human Services Research Institute
Deborah A. Dorfman, JD, Center for Public Representation
Paige Emerson, SDM Pilot Advisory Council
Amanda Benoit, SDM Participant
Maggy Walto, MS, Nonotuck Resource Associates
Room: Breathitt (Suite Tower–2nd Floor)

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Okay, now what?

- Took the idea to Kentucky Protection & Advocacy.
- Contacted Jonathan Martinis/National Resource Center for Supported Decision-Making.
- Need $...

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Funding Source

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- Fund for Excellence- provide funding to HDI staff to fund worthy initiatives for which other funding sources are not available.
- Grant application process
- Funded for one year
- Up to $10,000

My Choice Kentucky is Born!

- October, 2015
- Partners:
  - Kentucky Protection & Advocacy
  - National Resource Center/Jonathan Martinis
- Goal- Spread the work across Kentucky about supported decision-making.

Attended SDM Symposium the same month- got really overwhelmed

Okay, now what?

- Funding ended
- Still work to do
- Still no external funding
- So…

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Funding Source 2.0

Fund for Excellence to the rescue again!

In-Kind Support from:

- Southeast ADA Center
- Commonwealth Council on Developmental Disabilities

My Choice Kentucky 2.0

- Continue education
- Pilot group- support individuals and teams to implement SDM and work to restore rights, if applicable.
- Before long…

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Justice for…

Susie!

July 24, 2017

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Spreading the word with some help from our friends!

HDI SEMINAR SERIES

phone 859-257-3360 | email walt.bower@uky.edu

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Disability Law and Policy: Emerging Trends and Future Practice

Friday, September 22, 2017 1:00 – 3:00pm EST

Presenter: Peter Blanck, Ph.D., J.D.

prior individuals in the history of the University. He also is Chairman of the Burton Blatt Institute.

As people, we strive to have the authority to self-govern our lives and navigate the path toward our futures. For people with disabilities, this isn't always the case. There are many laws that shape the public discourse on the civil rights of people who have disabilities. This dynamic seminar will examine modern disability law and policy and the advancement of the fundamental rights people with disabilities have to fully participate in society. The seminar will also explore the disability rights movement and discuss current trends like Supported Decision Making, a process that empowers people to make life decisions with the help of friends, family members and trusted professionals.

Learning Objectives:

1. Learners will become familiar with the body of study on the efficacy of SDM as a fundamental human right.
2. Learners will have a deeper understanding of disability law and policy to advocate for the fundamental rights of people with disabilities to have full and equal participation in society.

CEU's are pending in Rehabilitation Counseling in conjunction with the Kentucky Office of Vocational Rehabilitation. CEU's are pending in Effective Instructional Leadership.

Registration: *Electronic registration will open* ***August 23, 2017****. Visit HDI Seminar Registration to register for the seminar. For help registering, contact walt.bower@uky.edu*

Burton Blatt Institute SYRACUSE UNIVERSITY

Southeast ADA Center

UK CENTER FOR EQUALITY AND SOCIAL JUSTICE

Kentucky Career Center Vocational Rehabilitation

You Don't Have To Do It Alone: Collaboration at Kentucky's UCEDD

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Laura Butler[1], Jonathan Martinis[2], Camille Collins-Dean[3] Bev Harp[3], Amy Cooper-Puckett[4]

[1]University of Kentucky [2]Syracuse University, [3]Kentucky Protection & Advocacy, [4]Kentucky Office of Autism

My Choice Kentucky

My Choice Kentucky is partnership between the Human Development Institute at the University of Kentucky (HDI), the Burton Blatt Institute at Syracuse University (BBI), and Kentucky Protection & Advocacy (P&A). The primary goal of this project to identify and implement supported decision-making (SDM) based supports and services for project participants, helping them retain or regain their right to direct their own lives, free from overbroad or undue guardianship. Participants use SDM to work with their natural supports and their service providers to identify specific goals and objectives designed to help them maximize, retain, or regain their right to direct their own lives, free from guardianship. They will then develop joint, collaborative and coordinated service plans identifying and implementing supports and services designed to help the person meet those goals and lead an independent, community-included life.

In this partnership, BBI provides technical and legal support to the project staff. BBI brings expertise in SDM and practical legal experience representing people in rights restoration cases using SDM. HDI is funding the project and coordinating the team members, in addition to evaluating the pre/post data. P&A is recruiting the project participants and providing direct support to the team.

Thus far, two people involved in the project have had their rights restored. Each had a public guardian prior to rights restoration. Three other people have been enrolled in the project and are in the process of forming their SDM teams. More participants will be enrolled in the coming months.

Success!

Susie posing with her dream board and her attorney and a member of team after successfully petitioning to have her rights restored. Read Susie's stories in the Summer/Fall issue of Exceptional Family Ky magazine.

INTRODUCTION

Collaboration and self-determination are core values of University of Kentucky's Human Development Institute (HDI). Here we have highlighted two projects on which HDI is currently collaborating with other agencies, in and out of Kentucky. My Choice Kentucky and Innovative Supports for Autistic Workers rely on significant input from self-advocates in promoting self-determination. Each of these projects is, at its heart, an effort to provide a path for people to live and work in the manner they chose. Both ISAW and My Choice Kentucky work to ensure that self-advocates are able to make their own life choices and have the support in place to bring those choices to fruition.

COLLABORATORS

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Burton Blatt Institute SYRACUSE UNIVERSITY

KENTUCKY P&A PROTECTION & ADVOCACY

ISAW innovative supports for autistic workers

Kentucky Office of Autism, DBHDID

Innovative Supports for Autistic Workers

Innovative Supports for Autistic Workers (ISAW) is a collaboration between Kentucky's Office of Vocational Rehabilitation (OVR), the Kentucky Office of Autism, and UK's Human Development Institute (HDI). Using a "train the trainer" approach, ISAW provides Business Service Teams across the state with information on autism and employment.

A unique feature of the project is its development and delivery by autistic self-advocates. In addition to the full time autistic staff person, ISAW partners with a team of six self-advocate consultants who provide valuable insight via lived experiences. From these self-advocates, Business Service Teams are able to learn, for example, that the accommodations autistic workers most need are rarely expensive or difficult to provide. Through their engagement in the project, autistic job seekers may gain greater access to hiring managers and have their needs better understood and accommodated.

ISAW training comprises both online training modules and in-person workshops. Modules describe key characteristics of autism and how these impact workplace experiences. Constructive approaches to common problems in interviewing and supervision are suggested. In-person trainings include real life scenarios and opportunities for discussion and further collaboration.

In October of 2017, ISAW worked with OVR, Kentucky Autism Training Center, and the Kentucky Office of Autism to produce Autism: Transitions Across the Lifespan, a Summit for Self-Advocates, Parents, and Professionals in Northern Kentucky. Having grown out of a series of "parent summits," this was the first such event in the state to include self-advocates at every stage of the planning process, and to provide a forum for all of these groups to share their knowledge and experience on an equal playing field.

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New Opportunities

WITH Foundation

Work for Inclusive and Transformative Health Foundation
(formerly Special Hope Foundation)

Request for proposals targeted toward supported decision-making.

Wait! We know some people!

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My Choice Kentucky: Making Decisions in Healthcare

- Partnered with the University of Louisville School of Medicine

- Created a team that included:
  - Young adults with intellectual & developmental disabilities
  - Subject matter experts
  - Family members

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Blood Draw Tool

- Encourage medical professionals to use SDM
- Facilitate plain language conversation
- Allow time for processing
- Published in multiple formats
- Lives on the My Choice Kentucky website- www.mychoiceky.org/toolkit

Kentucky WINGS

- Formed by legislative resolution (HJR 33)
- Started in July, 2018
- 'Friends of WINGS' recently started as a non-profit arm of WINGS

KENTUCKY WINGS
Working Interdisciplinary Networks of Guardianship Stakeholders

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State and National conversations are accelerating by late 2018…

…but, My Choice Kentucky's funding is ending.

Enter funding 3.0:

Commonwealth Council on Developmental Disabilities

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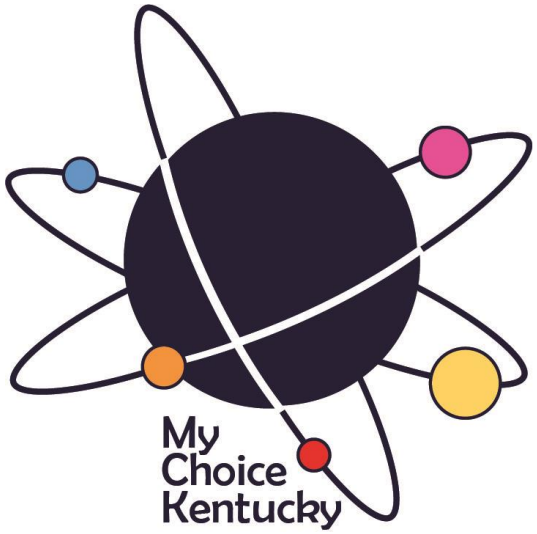
The NEW My Choice Kentucky



- Continue and expand project efforts.
  - Increase number of people who are receiving direct representation from P&A
  - Increase groups educated
  - Create materials for education to large and small groups
    - Flyers
    - Videos
    - Implementation guides

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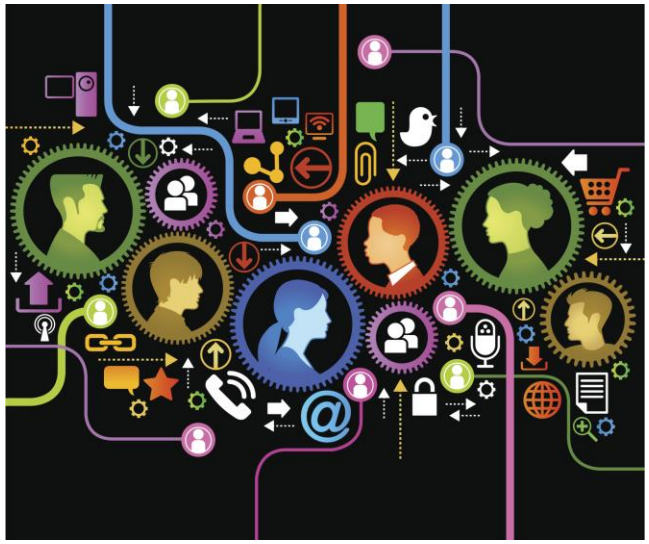
Partners, Collaborators, and Funders

- Kentucky Protection & Advocacy
- National Resource Center on Supported Decision-Making
- Burton Blatt Institute
- Southeast ADA Center
- University of Louisville School of Medicine
- Disability Right Texas
- WITH Foundation
- Commonwealth Council on Developmental Disabilities*



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Presentations: State & Local

- Self-Advocate groups
- Provider groups
- School systems
- DAIL Leadership
- KY ARC
- CCDD
- KY APSE

- KY Sibling Leadership network
- KY Centers for Independent Living (CILs)
- And then some!

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Presentations: National

- Webinar with National Resource Center
- Webinar for Best Buddies Jobs
- AUCD:
  - Poster- 2017
  - Presentation- 2018
- National Disability Rights Conference
- National Guardianship Association- *October, 2019*

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Tools and Resources

PRACTICAL Tool for Lawyers:
Steps in Supporting Decision-Making

The PRACTICAL Tool aims to help lawyers identify and implement decision-making options for persons with disabilities that are less restrictive than guardianship. It is a joint product of four American Bar Association entities – the Commission on Law and Aging, Commission on Disability Rights, Section on Civil Rights and Social Justice, and Section on Real Property, Trust and Estate Law, with assistance from the National Resource Center for Supported Decision-Making. Learn more about the PRACTICAL Tool and Resource Guide at www.ambar.org/practicaltool.

PRESUME guardianship is not needed.

- ☐ Consider less restrictive options like financial or health care power of attorney, advance directive, trust, or supported decision-making
- ☐ Review state statute for requirements about considering such options

Observations and Notes:

REASON. Clearly identify the reasons for concern.

Consider whether the individual can meet some or all of the following needs:*

Money Management:
- ☐ Managing accounts, assets, and benefits
- ☐ Recognizing exploitation

Health Care:
- ☐ Making decisions about medical treatment
- ☐ Taking medications as needed
- ☐ Maintaining hygiene and diet
- ☐ Avoiding high-risk behaviors

Relationships:
- ☐ Behaving appropriately with friends, family, and workers
- ☐ Making safe decisions about sexual relationships

Community Living:
- ☐ Living independently
- ☐ Maintaining habitable conditions
- ☐ Accessing community resources

Personal Decision-Making:
- ☐ Understanding legal documents (contracts, lease, powers of attorney)
- ☐ Communicating wishes
- ☐ Understanding legal consequences of behavior

Employment:
- ☐ Looking for, gaining, and retaining employment

Personal Safety:
- ☐ Avoiding common dangers
- ☐ Recognizing and avoiding abuse
- ☐ Knowing what to do in an emergency

Observations and Notes (List supports needed.):

*Adapted from University of Missouri Kansas City, Institute for Human Development, "MO Guardianship: Understanding Your Options & Alternatives," http://moguardianship.com.

Supported Decision-Making Teams: Setting the Wheels in Motion

By: Suzanne M. Francisco, Special Education and Disability Rights Advocate with Jonathan G. Martinis, Esquire

Introduction:

For thousands of years – going back to Ancient Rome – society treated people with intellectual disabilities as if they were unable to take care of or make decisions for themselves. Today, it is still expected that someone else – usually called a *guardian*, but in California, a *conservator* - will be appointed to make decisions for them. In fact, that is often the advice parents get when their children with disabilities turn 18: become their guardian/conservator as soon as possible. It doesn't *have* to be that way. This paper is about your options and actions you can take to help your children make their own decisions and direct their own lives to the maximum of their abilities.

I share this from my own experience. I am the proud mother of three children with disabilities. We have navigated our way through many systems, advocating for the tools, methods and resources they need to lead their best lives. I am the sister to a person with physical and mental illness. I watched with sadness when she was placed in a group home against her will, then shared her joy after she successfully fought to be released to her own supported apartment. I carry their experiences, their strength, and their values with me as contributing author and an educational advocate, where I help children and young adults receive the support and services they need to transition to adulthood.

In this paper, I will present ways to help your children *Set the Wheels in Motion* toward lives of independence. The journey starts with a question.

WHY NOT Guardianship/Conservatorship?

The difficulty with guardianship/conservatorship is that it takes away the person's Right to Make Choices, the basic right we all have to direct our lives to the maximum of our abilities. When people lose the right to control their lives, it's like they don't exist – someone else has the power to make

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Data source

NCI™ NASDDDS & HSRI

National Cor

DATA

Image courtesy of the Texas Council

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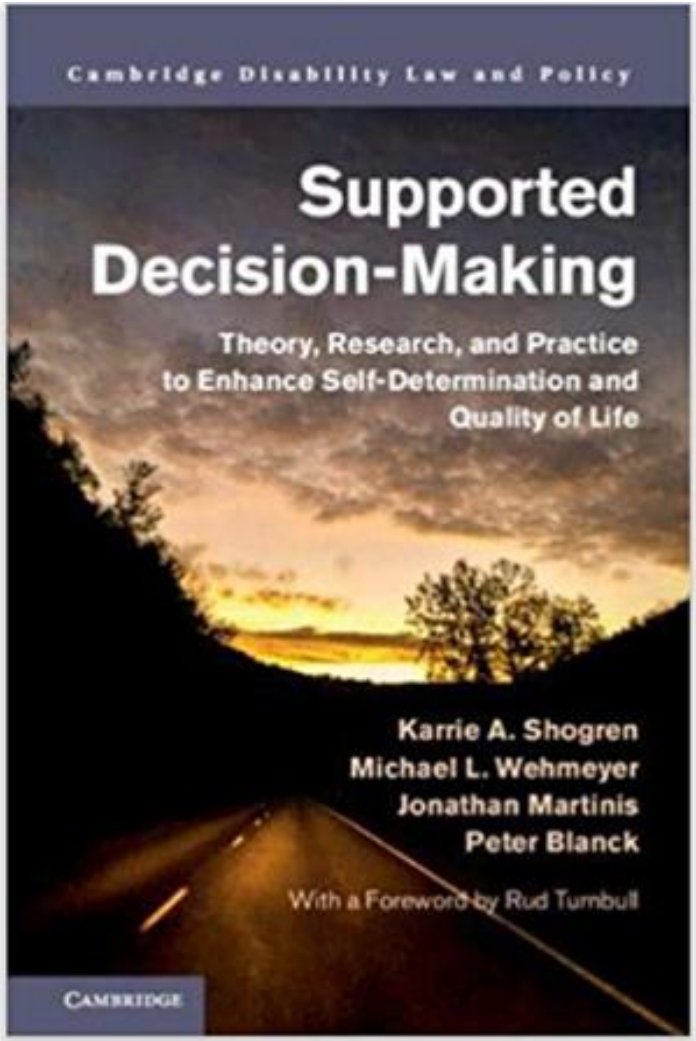

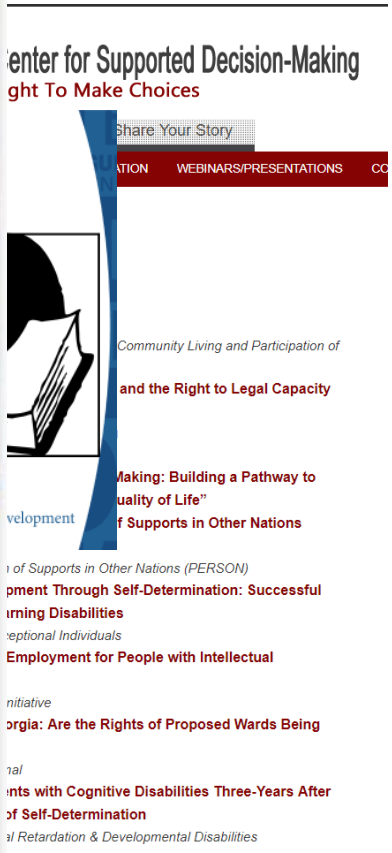

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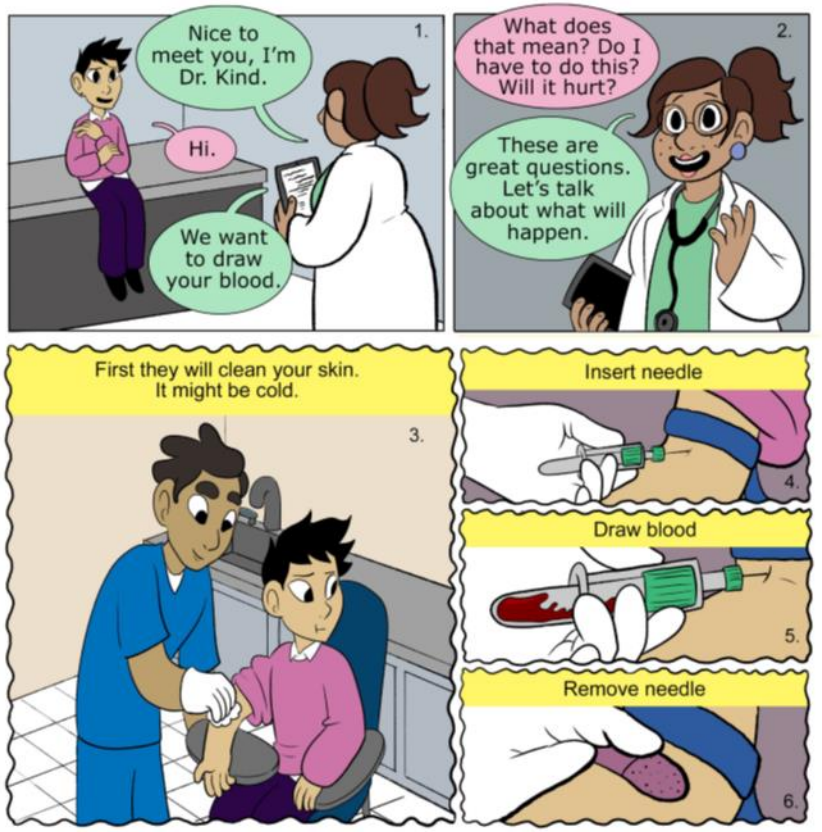
Tools and Resources

Vison Boards

Blood Draw tool



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SDM at Work in Kentucky

Susie:

- First person in Kentucky to have using SDM
- Was in state guardianship
- Thriving!

Advocacy **Works** Supported Decision-Making

Freed From Guardianship

A Kentucky First: Woman Wins Her Rights in Court Using SDM

Suzanne Heck wanted her rights back... and in the process the 22-year-old from Lexington became a pioneer and role model for those like her in Kentucky.

Shortly after Heck, who is diagnosed with a mild intellectual disability, reached adulthood, a Kentucky court took away her right to decide where she lived, what she did with her money and what happened to her body.

At the age of 18, she became a ward of the state.

So in March of 2017, Heck (her friends call her Suzie) and her support team contacted Kentucky Protection & Advocacy and requested its help with restoring her rights through Supported Decision-Making.

SDM is a way people can make their own decisions and stay in charge of their lives while receiving any help they need to do so. Supported Decision-Making is just a fancy way of describing how we all make choices.

Currently in Kentucky, there are over 4,500 adults in the state guardianship system, which is underfunded and severely over-burdened.

Many adults like Heck can make decisions for themselves with the support of a team. Heck's team consists of friends and paid caregivers through Kentucky's intellectual and developmental disability Medicaid waiver called Supports for Community Living.

She attends day services at an Adult Day Training facility in Lexington, lives in a home with two housemates and staff who assist her with daily living, as needed.

When Camille Collins, an Advocate with Kentucky Protection & Advocacy, became involved in Heck's case, Suzie's supporters had already begun functioning as a SDM team.

Team member Stacy Seale, a licensed psychological associate at Employment Solutions, submitted a psychological report with a petition to modify or terminate guardianship in Fayette County District Court.

In this report, Seale emphasized all of Heck's abilities and that she works with her team when making medical, personal and financial decisions.

"Ms. Heck does a wonderful job of seeking out her team and asking for their input on her current life decisions," Seale said.

Seale concluded that Heck, working with her SDM team, would no longer need a legal guardian.

In April, Heck attended a hearing to modify or terminate her guardianship order. Her state guardian attended and agreed with Heck's request.

Because the county attorney was not comfortable with the restoration, Collins requested that an attorney be appointed for Heck and that the hearing be postponed. The judge agreed.

Moira Mulligan, Heck's appointed attorney, worked with Collins and Heck's SDM team to learn how individuals with disabilities can use teams to support them in their ability to make decisions for themselves.

Heck also created a "Dream Board," which consists of photos of her SDM team members on one side and illustrations that represent her hopes and dreams on the other.

Her goals are no different from anyone else's – vacations, employment, and more time with family and friends.

As a ward of the state, most if not all of her goals and dreams would have to be approved by a guardian, forcing Heck to defend her goals.

That would mean meetings and hours

Winning Team: Suzie Heck holds her Dream Board with Lynn Hall and Moira Mulligan

SDM at Work in Kentucky

Dawn:

- Using SDM to avoid guardianship
- Works on our team

Howard:

- Father was guardian, moved to state guardianship
- Married with a child now; doing great!

SDM at Work in Kentucky

Eli:

- State guardianship, transitioned from foster care
- Struggling with new independence
- MCK team wanted to delay hearing

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SDM at Work in Kentucky

Joseph:

- Mother was guardian
- Both wanted it removed
- Lives with a Family Home Provider
- More mature and ready to handle responsibilities now, at age 26, than at age 18 (shocking, right?)

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Bickman celebrates his freedom

First In Mercer County To Have Rights Restored

Jennifer Marsh
Herald Staff
jmarsh@harrodsburgherald.com

Joseph Bickman of Burgin made local history February when he became the first adult with an intellectual disability in Mercer County to have his rights restored.

Imagine becoming an adult and not having the right to basic self-determination. Bickman didn't have to imagine this. The commonwealth decided where he lived and what he did with his time. However, with help from his foster family, Bickman became the first local to win his independence.

"It was a first in Mercer County," said Bickman's foster father, Walt Barbour. "Joseph is now part of a support decision making team."

Barbour, who is an advocate for supported decision making, met Bickman through his work at a Lexington Day treatment facility called Employment Solutions.

"He was unhappy with his living environment and it was creating behavior issues," Barbour recalled. "He is a young man who loves to be outside and he was living in a staffed residence with older gentlemen. It just wasn't the right fit."

Barbour said Bickman was kept heavily medicated and his activity was limited.

"He couldn't go outside due to the busy area surrounding the house," Barbour said. "We started taking him home with us on the weekends and things developed from there."

After becoming a foster family for Bickman, the Barbours started petitioning the state to restore his rights.

"We received help from the Kentucky Department for Advocacy," Barbour said. "It was a long process and we were denied the first time."

Bickman is now able to make decisions as part of a supported decision making team. It gives the individual more control over their own life while also protecting them. The University of Kentucky has created a regional program with support from the National Resource Center for Supported Decision-Making.

Bickman is originally from Russia and was two when he was adopted. His adoptive family resides in Winchester.

The Harrodsburg Herald/Jennifer Marsh

Joseph Bickman is the first person with intellectual disabilities in Mercer County to have his rights restored. "I feel like I have full control over my life now," Bickman said.

"We have a great working relationship with his adoptive parents," Barbour said. "They are very supportive of Joseph's decisions."

Barbour said Bickman is no longer on any medications. He is extremely social and busy with his life in Burgin.

"I feel like I have full control over my life now," Bickman said. "I know I still have to ask permission and be respectful of how things work, but I like having rights."

Bickman is currently working part-time in cardboard production and loves to listen to music and drive his golf cart.

"I like my life," said Bickman, who has fallen in love with Lake Herrington since moving in with the Barbour family. "I like rights and I like it here."

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Lessons Learned

- Good partners are essential!

National Resource Center For Supported Decision Making

EVERYONE has the Right To Make Choices

UNIVERSITY OF LOUISVILLE
SCHOOL OF MEDICINE

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Burton Blatt Institute
SYRACUSE UNIVERSITY

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Lessons Learned

- Don’t reinvent the wheel!

Lessons Learned

- You HAVE to talk about guardianship

Guardianship is Not…

Kentucky Statute

387.640 Duties of limited guardian or guardian.

– It shall be the general duty of the limited guardian or guardian to carry out diligently and in good faith the specific duties and powers assigned by the court and to:

(1) Assure that the personal, civil, and human rights of the ward are protected; and

(2) ***Encourage the ward to:***

(a) Participate to the maximum extent of his abilities in all decisions which affect him;

(b) Act in his own behalf on all matters in which he is able to do so; and

(c) Develop or regain, to the maximum extent possible, his capacity to meet the essential requirements for his physical health or safety, and, if impaired, his capacity to manage his financial resources.

Effective: July 1, 1982
History: Created 1982 Ky. Acts ch. 141, sec. 15, effective July 1, 1982.

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Lessons Learned

- Institutional buy-in is a must
  - Court systems
  - Department for Aging and Independent Living
  - School systems
  - Medical/mental health professionals
  - Disability services
  - Aging services

Lessons Learned

- Trust our gut instinct.
- Don't race to the courtroom.
- Better to do it right than do it fast:
  - Individuals
  - Policy
  - Legislation
- Teach people to fish.

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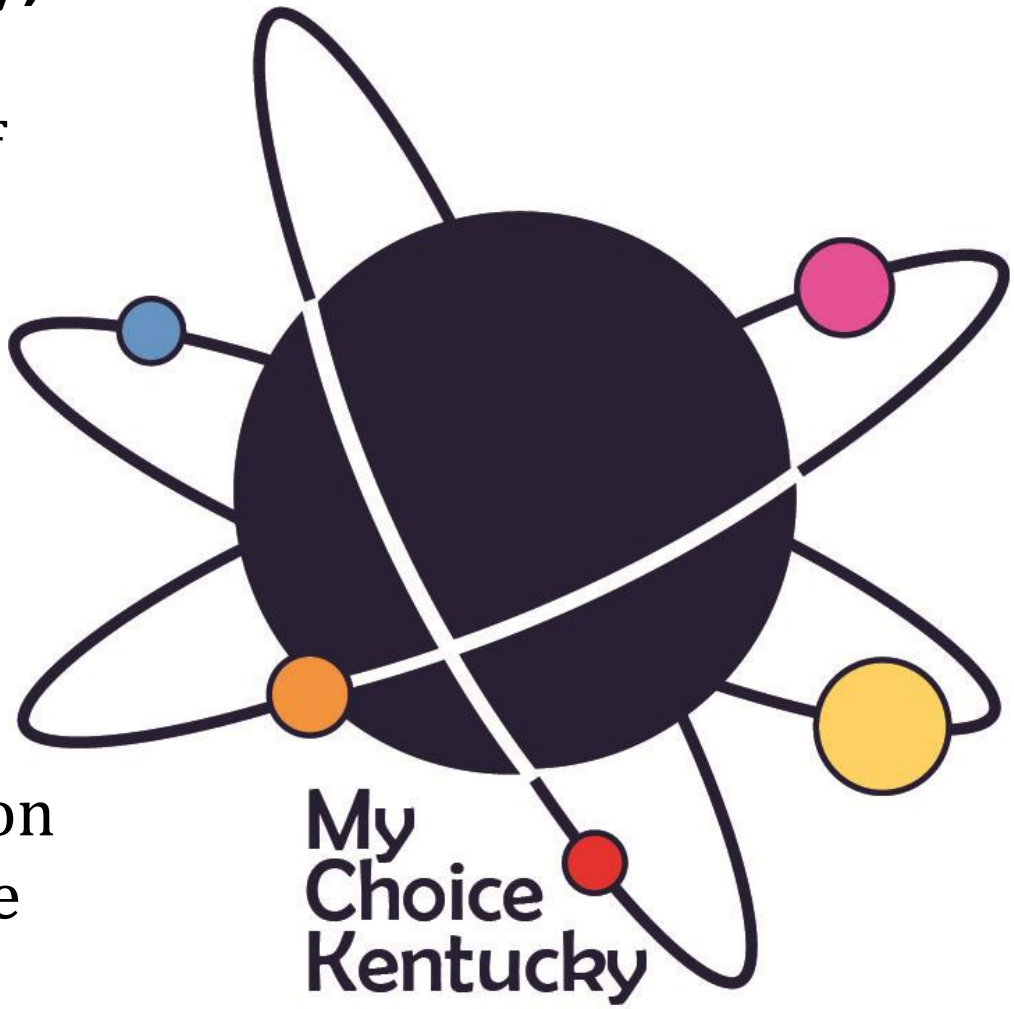
Okay, now what?

- Keep doing more of the same
- Grow
- Create a larger network
- Connect to more state & national partners
- Work to influence policy and legislation
- Create a sustainable system



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Questions?

Contact

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