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

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Agenda

• Overview of project history

• Partners, Collaborators, and Funders

• Useful Tools and Resources

• SDM at Work in Kentucky
How We Got Here

Program
Making a Difference

Through Research, Practice, and Policy

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, FAIAID, 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
Maggie Walto, MS, Nonotuck Resource Associates

Room: Breathitt (Suite Tower–2nd Floor)
Okay, now what?

- Took the idea to Kentucky Protection & Advocacy.
- Need $...
Funding Source

- 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...
Funding Source 2.0

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...
Justice for...

Susie!

July 24, 2017
Spreading the word with some help from our friends!

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.

Human Development Institute
Seminars Series

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.

CEUs are pending in Rehabilitation Counseling in conjunction with the Kentucky Office of Vocational Rehabilitation. CEUs 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 wallt.bower@uky.edu
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!
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
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
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

• CCDD •
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
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*
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!
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
Tools and Resources

PRACTICAL Tool for Lawyers: Steps in Supporting Decision-Making

This 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.nembac.org/practicaltool.

PREMISE. Guardian is not needed.
- Consider less restrictive options like financial or health care power of attorney, advance directive, trust, or supported decision-making
- Review state statutes for requirements about considering such options

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
  - Maintaining hygiene and diet
  - Avoiding high risk behaviors
  - Relationships: Avoiding or limiting contact with abusive people
  - Making safe decisions about sexual relationships
  - Community Living: Living independently
  - Maintaining habitable conditions
  - Accessing community resources

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

Employment:
- Job readiness
- Employment training
- Job search

Personal Safety:
- Maintaining a safe physical environment
- Making safe decisions about sexual relationships
- Making safe decisions about friends
- Making safe decisions about sexual relationships
- Making decisions about community living

Observations and Notes:
(List supports needed)

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
Tools and Resources

Data source

NCI

Supported Decision-Making
Theory, Research, and Practice to Enhance Self-Determination and Quality of Life

Cambridge Disability Law and Policy

Karrie A. Shogren
Michael L. Wehmeyer
Jonathan Martinis
Peter Blanck

With a Foreword by Rud Turnbull

Human Development Institute
Tools and Resources

Vison Boards

Blood Draw tool
SDM at Work in Kentucky

Susie:

- First person in Kentucky to have using SDM
- Was in state guardianship
- Thriving!
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
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?)
Bickman celebrates his freedom
FIRST IN MERCER COUNTY TO HAVE RIGHTS RESTORED

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."
Lessons Learned

• Good partners are essential!
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.
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.
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
Questions?
Contact

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