



LTSS Lunch & Learn - Supported Decision Making

Date

Friday August 27, 2021, 12 p.m., virtual meeting

Presenters

Melissa Keyes, Executive Director, Indiana Disability Rights

Learning Topics

What is supported decision-making?

Why do we need decision-making supports?

How can we support decision-making in Indiana?

Agenda

1. Welcome and Meeting Purpose
2. Supported Decision Making
3. Questions and Discussion

The presentation slides will be shared along with the minutes.

Summary of important facts from the presentation

Melissa Keyes, Indiana Disability Rights, Executive Director

The presentation opens with an icebreaker activity to demonstrate that everyone has things that are important to them, and those things are individualized. Decision-makers have a big responsibility to make decisions quickly and often with little input from the individual.

Supported decision-making is defined in Indiana Code § 29-3-14-1 as “the process of supporting and accomodating an adult in the decision-making process to make, communicate, and effectuate life decisions, without impeding the self-determination of the adult.” In plain language, it is accommodation to help people make decisions, using a supporter, but that individual retains all decision-making authority. Supported decision-making can be used by anyone who needs help making decisions.

The concept of supported decision-making can be used within many decision-making arrangements, with a variety of supports. Capacity to make decisions exists on a spectrum and can be determined by several factors including the specific situation, complexity, and other internal and external factors. Capacity can change over time based on skill acquisition as well. Supported decision-making should be as individualized as possible so we are not restricting someone’s ability to make decisions. We should always start with the least restricitve option but provide as much support as needed.



Guardianship is not the only option available for supported decision-making. It is often the default option, but the goal is to start with the least restrictive options, which may be used in combination with one another and change over time.

The least restrictive options are more flexible, and support independence and interdependence. These can be formal or informal. They can include providing technology or planners, or having a neighbor check in. A slightly more formal support would include a supported decision-making agreement, such as a Power of Attorney (POA) or trust account. Indiana does not have a specific form for this agreement, but Indiana Disability Rights has a template that can be used by the public and can be modified for individual needs. The most restrictive option is through the court system. Limited guardianship is available, but is not used as often as it could be. Indiana does not have many legally required standards for guardianship; but there is a national guardianship association and professional guardians. Full guardianship can still cover a full spectrum of decision-making but can be difficult to revoke once implemented. Less restrictive alternatives can be shifted and moved as needed. Guardianship can be revoked through the death of the person under guardianship or if that person can show they legally do not meet the definition of needing guardianship.

Supported decision-making is a human rights issue. The United Nations Convention on Persons with Disabilities establishes that the right to self-determination is essential. Supported decision-making shows health and wellbeing benefits as well.

Many people are unaware of supported decision-making and our system is not set up to consider it as an option. It is easy to gain guardianship over someone, but very difficult to terminate it. Indiana was very progressive in defining supported decision-making but the guardianship code is inadequate. It does not provide many protections for people at risk of guardianship and guardianship is often determined by county laws. The code also lacks requirements for representation of the person at risk of guardianship. Guardian Ad-Litem are available, but they are not an advocate for the person. They provide recommendations to the court. There are minimum rules and no standards or certifications on who can serve as a guardian. There is also little oversight and accountability for guardians.

Questions/Answers

IAAAA: There are specific administrative actions that DDRS and the DA can take regarding the training of care managers and options counselors and there is a proposal in the plan you have been working on to change the culture around guardianship, including education and training.

Indiana Disability Rights: For the past two years, we have been working on a grant from the Administration for Community Living (ACL) to develop a state plan to expand the use of supported decision-making and the least-restrictive alternatives for individuals with disabilities and older adults. We are almost at the end of the grant cycle, and will be submitting the plan to ACL, as well as starting to implement it. Education is a huge component, and people need to be made aware of the available options. The pathways to guardianship need to be reviewed and disrupted through education, outreach, and capacity building. Since guardianship requires a court, we are looking at diversion work through options counseling and education.



FSSA: Thank you. It will be interesting to see how this all works out and it is great to see it take shape.

IAAAA: To add on to what IDR said about health care decision-making and that's why this is so important in relation to MLTSS –we want to make sure that this concept stays connected to MLTSS.

FSSA: I was reflecting on that; thank you for making the connection. We have to pay attention to decisions, education, access, and options as we head into MLTSS. This is about honoring choice.

INSILC: It is really important to make sure those impacted also receive education on the least restrictive options.

Indiana Disability Rights: Absolutely. I really advocate for early and often for self-determination, particularly for children who turn into adults with no supports, and then the parent becomes the guardian. We would like to see self-direction happen really early.

FSSA: This brings a few pieces together. All of us have our copies of the 2014 regulations from CMS and we focus on the settings rule, but there are significant regulations around person-centered planning and what that process should look like. It should be directed by the person at the maximum extent possible.

Closing comments

Thank you to IDR for bringing this topic forward. Please stay tuned for more information about next month's Lunch & Learn.



Stakeholder Attendees

Amber O'Haver, INSILC
Beth Skinner, CICOA Aging & In-Home Solutions
David Sklar, Alzheimer's Association - Greater Indiana Chapter
Elizabeth Eichhorn, Indiana Health Care Association (IHCA)
Eric Essley-, LeadingAge Indiana
Judy Pippin, Kopka Pinkus Dolin
Karly Sciortino-Poulter, The Arc of Indiana
Kathleen Unroe, Indiana University
Kelli Tungate, Caregiver Homes of Indiana
Kristen LaEace, Indiana Association of Area Agencies on Aging (IAAAA)
Lori Haug, Miller's Health Systems, Inc.
Mark Lindenlaub, Thrive Alliance
Mary Ann Marron, Suburban Health
Melissa Keyes, Indiana Disability Rights
Michelle Stein-Ordenez, Indiana Association for Home and Hospice Care
Tauhric Brown, CICOA Aging & In-Home Solutions
Teresa Lorenz, Thrive Alliance
Terry Miller, HOPE
Wanda Prince, Golden Living Centers
Zach Cattell, Indiana Health Care Association (IHCA)

FSSA Attendees

Allison Taylor
Amy Rapp
BreAnn Teague
Brenda Buroker
Carissa Atherton
Cathleen Nine-Altevogt
Darcy Tower
David Simpson
Erica Ng
Erin Wright
Hamilton Smith
Jessica Keyes
Jessica Murdock
Jim Gavin
Kamilah Harruna
Katie Hunter
Kevin Hancock
Kim Opsahl
Leslie Huckleberry
Lucy Morrell



Lynn Clough
Maggie Novak
Melinda Flowers
Meredith Edwards
Michael Gargano
Mindy Flowers
Mitchell Reller
Peggy Welch
Rebecca McClaren
Reiko Osaki
Roxanne Alpha Manzi
Sarah Renner
Shannon Effler
Steve Counsell
Tom Arnold
Vanessa Convard