



Lunch & Learn Webinar: Informed & Supported Decision Making: A Primer

Presenters:

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This webinar is being sponsored by the NCCDD and North Carolina Money Follows the Person Project (NC MFP), a Medicaid project that assists Medicaid-eligible North Carolinians who live in inpatient facilities to move into their own homes and communities with supports.



Today's Presenters



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Today's Objectives

- Define Informed Decision Making (IDM)
- Define Supported Decision Making (SDM)
- Why Informed and Supported Decision Making?
- How can direct support professionals can engage in both IDM and SDM
- Describe how decisions are important for all people and that people with disabilities have a right to their own decisions in life

What is Informed Decision Making?

(A comprehensive definition for Direct Support Professionals)

- **Informed decision making is a process where a person supported has obtained information and knowledge about a situation or problem**
- **With the assistance of a direct support professional or other person, the person supported understands the choices available to them and the outcomes possible**
- **When they make a final choice it reflects their personal values, not those of the people assisting or supporting them**
- **Finally, it is the acceptance of the associated responsibility and risk of the decision. This decision is their decision alone and non-coerced by the professional.**

Supported and Informed Decision Making



When people are supported to make decisions for themselves, they are seen as more capable by others.

When we are not allowed to make our own decisions or when someone else makes our decisions for us, we are seen as less capable and as having less value in community.

2014 INDEPENDENT BUT NOT ALONE: A GLOBAL REPORT ON THE RIGHT TO DECIDE
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What is Supported Decision Making?

- Supported Decision Making (SDM) is “a series of relationships, practices, arrangements and agreements of more or less formality and intensity designed to assist an individual with a disability to make and communicate to others decisions about the individual’s life.”

(Robert Dinerstein, Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision Making, 19 HUMAN RIGHTS BRIEF 8, 10 (Winter 2012))

What is Supported Decision Making?

- Support and services that help an adult with a disability make his or her own decisions
- Utilizes chosen trusted family members, friends, professionals or others to fill the role of supporter to:
 - Help understand issues and choices
 - Ask questions
 - Receive explanations
 - Communicate decisions

(Blank and Martinis 2015; Dinerstein 2012; Salzman 2011)

Principles of IDM and SDM

- Everyone uses support to make decisions, regardless of disability.
- People with disabilities do not lack capacity simply because they have disabilities
- Everyone has a will and preferences
- Will and preferences are the core of decision making abilities
- Will and preferences can be expressed by the person or understood by others who know the person well and are in a voluntary, trusting and committed relationship with the person

(Bob Fleishner, Center for Public Representation, July, 2015)

Highlights of IDM and SDM

- There is no “one size fits all” method of Informed or Supported Decision Making
- It requires working with each person (decision maker) to identify where help in making decisions is needed or desired and helping that person find trusted supporter(s) to provide that help.
- Solutions are different for each decision maker

Highlights of IDM and SDM

- IDM is informal however a skill to learn and practice
- SDM can be formal or informal
- Formal SDM agreements can be drafted that record the decisions a decision maker wants help with, who the decision maker has selected to be a supporter for that decision, and how information will be communicated on the decision makers decision
- It is not a stagnant process but should be fluid
- Formal SDM agreements should be reviewed regularly

Why Informed and Supported Decision Making?

- 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)
- People with greater self-determination are:
 - More independent
 - More integrated in their communities
 - Healthier
 - Better able to recognize and resist abuse

(Powers et al., 2012; Shogren, Wehmeyer, Palmer, Rifenshank, & Little 2014; Wehmeyer & Shwartz, 1997 & 1998; Wehmeyer & Palmer, 2003; Khemka, Hickson & Reynolds, 2005; Wehmeyer, Kelchner & Reynolds, 1996)

Why Informed and Supported Decision Making?

- When denied self-determination, people can:
 - Experience “low self-esteem, passivity and feelings of inadequacy and incompetency,” decreasing their ability to function. (Winick, 1995, p.21)
- Decreased life outcomes
 - Overbroad or undue guardianship can cause a “significant negative impact on...physical and mental health, longevity, ability to function, and reports of subjective well-being” (Wright, 2010, p. 354)

Supported Decision Making in the U.S.

- SDM is new to the United States
- Legislation for SDM
 - Texas first state to pass legislation on Supported Decision Making
 - Delaware, and D.C. have had bills passed on SDM in the past two years
- Studies of Supported Decision Making
 - Studies of SDM are occurring in Virginia, Maine, and New Hampshire
- Pilot Projects
 - The Nonotuck Resource Associates/Center for Public Representation pilot in Massachusetts
 - The SDMNY pilot with Hunter College, NYSACRA and Arc of Westchester in New York

How Can DSPs Support IDM and SDM?

- Practice informed decision making
- Recognize that people make many decisions every day
- Every one has the right to make a bad decision – And to learn from it!
- When a person has a guardian, respect the role of the guardian, however, remember your first allegiance is always to the person you support.
- Help the person you support communicate the decisions that **they** want made on their behalf.

Jenny Hatch



- Virginia – 2013
- Assigned a guardian
- Fought to have her civil rights restored
- One of the first successful rights restoration cases in the U. S. because she was already successfully using supported decision-making

(Jenny Hatch Justice Project, Quality Trust,
www.dcqualitytrust.org)

Resources for Learning More

- Supported Decision Making – www.supporteddecisionmaking.org
- DC Quality Trust – www.dcqualitytrust.org
- National Guardianship Association, Inc. www.guardianship.org
- National Alliance for Direct Support Professionals www.nadsp.org



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<https://nccdd.org/supported-living-making-the-difference.html>